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# Examining Causes for Readmission in the Internal Medicine Population from the Patient Perspective

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UNIVERSITY OF CALGARY

Examining Causes for Readmission in the Internal Medicine Population from the Patient  
Perspective

by

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## **Abstract**

A significant number of internal medicine patients discharged from acute care require readmission within 30 days. Current readmission rates create a significant burden to the healthcare system. Identifying causes of readmission can inform health care practice to mitigate factors associated with readmission and improve care and outcomes for patients and families. A literature review reveals a wealth of quantitative research from the perspective of healthcare practitioners. Less is known about the perspectives of internal medicine patients, particularly in Canada. As such, understanding why readmissions occur within 30 days of discharge within this patient population is limited. Avoiding readmission needs to be guided by strategic discharge practices that are informed by relevant research studies. Specifically, further research into patient perspectives on why they are readmitted warrants further qualitative investigation. This study is a qualitative, thematic analysis, designed to explore internal medicine patients' perspectives about readmission to hospital. Knowledge from this study can inform healthcare practice by informing upstream, proactive, pre-emptive measures to address patients' and health system needs.

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## **Dedication**

This thesis is dedicated to, and in loving memory of my parents, Tom and Joanne de Boer.

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## **Chapter 1: Introduction**

Acute care readmission is a national issue that contributes significantly to patient and healthcare system burden. The Canadian Institute for Health Information (CIHI, 2018) reports nationwide 30-day readmission rates for all patients in the 2016-2017 fiscal year to be 9.1%, or 1 in every 11 patients; the total cost associated with these readmissions is over 1.8 billion dollars. There are many diverse causes associated with acute care readmission (Allaudeen et al., 2011; Harrison et al., 2016; Hoyer et al., 2017; Leppin et al., 2014), which means there are no simple solutions to burdens on the health system or those who require readmission. In addition to system and fiscal burdens of readmission, avoidable readmission can represent a setback for patients and families in their healing trajectory. Considering the burdens associated with readmissions, it is necessary to question whether readmissions within 30 days of discharge from acute care can be reduced or avoided through improved healthcare practices such as enhanced discharge planning and transitioning support (Cakir et al., 2017; Hoyer et al., 2017; Jeffs et al., 2014; World Health Organization, 2016).

The internal medicine population represents an important acute care demographic in examining 30-day readmission rates. Within Alberta Health Services (AHS) Calgary zone, the mean readmission rate for internal medicine patients has gradually increased since 2006, ranging from approximately 14.2 % to approximately 15.0% in the first quarter of 2018 (CIHI, 2018). It is unclear why the readmission rate for internal medicine patients is higher than the national average for patient readmissions overall. Although there are factors associated with this patient demographic that may be able to explain the higher-than-average readmission rate, such as an aging population and multimorbidity (Cakir et al., 2017; Kone Pefoyo et al., 2015; Turner et al.,



2011; Vat et al., 2015), it is currently unclear why the readmission rate for AHS is higher than the national average.

In this thesis, I describe research into the experiences of people encountering illness and readmission to an acute care, internal medicine context. I have undertaken this research to fulfil the requirements for my Master of Nursing degree, to become an advanced practice nurse (APN). Advanced practice nurses (APN's) with clinical expertise in internal medicine have a comprehensive understanding of patient complexity within this population, in-depth knowledge of multidisciplinary team function, and are well positioned to develop and undertake studies exploring causes for 30-day readmissions rates.

### **The Purpose of the Study**

Within the internal medicine patient population, there is a significant readmission rate within 30-days post initial discharge from hospital. Current readmission rates reflect a substantial cost burden to the healthcare system, yet there is relatively little local knowledge about what influences readmission. Existing knowledge about readmission is mainly informed by research undertaken with clinical and professional health system staff. This research does not account for patients' experiences that might influence readmission.

The purpose of this study is to learn from patients their perspectives of their readmission to hospital. Exploring these perspectives will add to a body of literature that informs the practices of nurses and physicians as well as provide useful insights for health system modifications, policy development, and further study. Causes for readmission within 30 days post-discharge needs to be investigated from multiple perspectives. While progress has been made in investigating the issue from a quantitative, health systems perspective, a gap exists in understanding patients' perspectives. This is a significant gap in the literature, given that

evidence-informed nursing practice requires insight into how patients understand and engage with nursing care (Barker et al., 2016). Nurses are challenged to understand and evaluate how internal medicine patients experience the complex world of the healthcare system so that the quality and safety of inpatient care can be improved, and to optimize the transition from acute care to community.

### **Significance of the Study**

At the turn of the 21<sup>st</sup> century, people are living longer with complex disease than at any other time in history. Advancements in acute care medicine have greatly reduced patient mortality (Mercer, et al., 2016) and thus changed the face of healthcare delivery. As a result, patients present to healthcare services with increased acuity and complexity. For internal medicine patients, acuity and complexity is a consequence of far-reaching disease processes and living with chronic complex disease (Ho et al., 2015). Chronic complex disease (CCD) is defined as “a condition involving multiple morbidities that requires the attention of multiple health care providers or facilities and possibly community (home)-based care” (Sevick et al., 2007, p. 439). Multimorbidity is a kind of complexity experienced by internal medicine patients. Multimorbidity is commonly described as the co-occurrence of two or more chronic conditions in an individual (Feely et al., 2017). The terms CCD and multimorbidity are often used interchangeably in the literature <sup>1</sup>.

As patients are living longer, healthcare services need to be able to respond to CCD. CCD and multimorbidity are increasingly prevalent in Canada (Kone Pefoyo et al., 2021; Lebenbaum et al., 2018; Steffler et al., 2021), and around the world (Kudesia et al., 2021;

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<sup>1</sup> In this study I use the term, chronic complex disease. Where reference is made to multimorbidity, it is to be consistent with the language of the authors being referenced.

Prados-Torres et al., 2018). CCD emerges from a myriad of etiological factors (Shippee et al., 2012). It can potentiate the progression of coexisting disease processes (Yokota et al., 2016) and is associated with polypharmacy (Di Angelantonio et al., 2015; Prados-Torres et al., 2018) and greater healthcare utilization (Kudesia et al., 2021; Palladino et al., 2016). People with multimorbidity represent an increasingly younger patient demographic (Kone-Pefoyo et al., 2021; Steffler et al., 2021) who require a growing proportion of healthcare spending (Hajat & Stein, 2018; Thavorn et al., 2017). It is associated with reduced health-related quality of life (Mondor et al., 2016; Ploeg et al., 2017) and higher mortality risk (Di Angelantonio et al., 2015; Vetrano et al., 2020). The disease trajectory arising from multimorbidity is variable. Patients can present for care in states between stable and severely incapacitated (Yano et al., 2021). Due to the complexity of CCD, disease management is reliant on increasingly involved treatment plans. CCD places significant burden on patients, loved ones, and the healthcare system (Howard-Anderson et al. (2016); Pefoyo, et al., 2015; Turner, et al., 2011; WHO, 2016).

With the fluctuating burden of illnesses and an aging population, the practice of internal medicine has increasingly relied on expertise from multiple medical specialties, as well as numerous interdisciplinary team professionals. This model of care has contributed to fragmented healthcare delivery (Nardi, et al., 2007). It is at this juncture that the emerging issue of individual experience from the perspective of the internal medicine patient becomes an important area for research inquiry.

Internal medicine patients with CCD can find activities of daily living challenging. Their illnesses can mean they need a variety of assistance from diverse support systems. It is common for patients to have to work with specialized equipment, such as home oxygen, continuous or bi-level positive airway pressure devices, and orthotic devices to manage chronic disease.

Additionally, pharmacological interventions for this patient demographic tend to be complex, which can place further responsibility on patients and families. The presence of multimorbidity and the overall challenges of managing transitions from internal medicine settings to home, means that the healthcare system needs to engage with aspects of patients' experiences that contribute to readmissions within 30 days of being discharged.

Issues of healthcare burden are compounded by an ageing population. The CIHI (2018) reported the average spending on individuals 80 years of age and older is nearly eight times more than is spent on someone between one and 64 years of age. Therefore, exploring this topic seems worthwhile given that it may offer insight into avoidable suffering that leads to further economic cost. The experience of managing the transition from the internal medicine setting to home can be complicated and confusing for CCD patients (Doos et al., 2015). Accordingly, it is important to understand how patients can be supported through this transition in a way that might reduce need for or length of readmission.

To summarize to this point, this study is significant because it addresses a perspective that is under-represented in the literature. Understanding patients' experiences related to readmission can offer important insights that help nurses to contribute to lessening the personal, familial, and systemic burdens of readmission. The knowledge that comes from understanding patients' experiences can inform practice. While in hospital and following discharge, each patient experiences an individual process of complexity due to CCD, taking varied paths through the healthcare system. Patient insights are vital in understanding where potential gaps in care may occur and in supporting patient centered care. The forthcoming literature review shows how current literature is limited in its capacity to inform practice in this way, since most of it has been conducted with clinical providers and services. Exploring patients' experiences through a

qualitative lens can offer a different, perhaps more humanistic perspective, on what contributes to readmission for patients with CCD.

## **Chapter 2: Literature Review**

A review of the literature exploring internal medicine patients' perspectives in relation to 30-day readmission exposes important gaps in current research. Limitations of the existing literature include a scarcity of Canadian research, a body of research that is overgeneralized to all populations of patients, or that is lacking in specific detail. Within the limited existing literature where patients' perspectives have been sought, several common themes emerge when patients describe their perceptions of why they were readmitted within a short period following their initial discharge. Overall, patients have expressed concern over a lack of discharge education, a lack of readiness for discharge and, to a lesser extent, mental health issues and social support.

### **Discharge Education**

Patient education is a key competency for nursing practice and a necessary intervention for CCD patients. Patients with CCD need theoretical and practical knowledge for day-to-day management of their health needs. Literature suggests that successful health maintenance requires patients and their significant others to have detailed knowledge about symptoms to make decisions about health management. In a cross-sectional study, researchers found that patients' knowledge was inadequate at discharge due to discharge teaching being standardized to a specific disease population as opposed to being tailored to the unique learning needs of individual patients (Kangiovi et al., 2012). The researchers recommended enhanced collaboration between acute care and the community and for healthcare professionals to modify discharge education to meet individual learning needs. Interestingly, 86.4% of study participants felt they were prepared for the transition home prior to discharge from acute care. However, the most common reported issue upon patient's readmission was the realization that they were unprepared for the challenges they encountered after discharge. A limitation of the Kangovi et al.

(2012) study was that the patients' perspective about what lack of preparedness meant and how it was experienced. The researchers did, however, highlight the value of surveying patients on readmission to gain a fuller picture of what patients thought could have prevented readmission.

One of the few qualitative studies available was conducted in Sweden. Flink and Ekstedt (2017) found that while the multidisciplinary team was effective in planning and organizing practical details of the discharge process among fellow healthcare professionals, patients were often uninvolved and/or unaware of discharge planning. Furthermore, in the same study, patients on medical wards at three different hospitals noted a lack of education on practical knowledge about disease management. Researchers recommended additional support, by way of inpatient or outpatient healthcare teams, could support more successful discharge transitions.

The literature suggests that patient education is an important and necessary aspect of care, to help patients learn about, understand, and manage their conditions. Cakir et al. (2017) conducted a qualitative study with 80 patients readmitted to an acute care hospitalist service in Chapel Hill, North Carolina. The researchers found 9.5% of readmitted patients were unaware of what their disease process reflected and what to expect in terms of symptoms. While 20.6% of patients in the study knew common signs and symptoms, they were unaware of what they ought to do or whom to contact if symptoms became worse. Howard-Anderson et al. (2016) analyzed 230 surveys of cardiac and general medicine patients admitted to an academic medical centre in Los Angeles. In their study, 29% of readmitted patients could not remember their physician discussing discharge related content with them, and 35% did not recall whether they received any discharge related paperwork; it is not clear whether these results reflect a lack of instruction or a lack of patient retention. The findings of this research and its gaps suggest it is important to

consider patients' experiences to explore how they receive and process information and how educational resources might be received and interpreted as useful or unhelpful.

Enhanced discharge education has been shown to reduce readmission rates. In an US-based randomized control trial (RCT) with 227 patients with systolic heart failure, researchers found patients who received one hour of individual one-to-one cardiac education by a nurse educator prior to discharge retained a significantly higher amount of disease-specific knowledge when compared to standard discharge teaching (Kommuri et al., 2012). In practical terms, this one hour of focused education was shown to reduce avoidable suffering and financial burden to the health care system. The study's authors did not consider CCD as a variable but did identify an important connection between the quality of education and knowledge retention among patients. What patients perceived as "quality" (or helpful and necessary) education in the context of CCD remains unknown.

Other research investigating causes for readmission also points to patient education as being important. Suffoletto et al. (2014) conducted a descriptive qualitative study using a convenience sample of 135 patients. They found approximately 10% of patients readmitted to the emergency department of an urban US hospital (within 30 days of discharge from any affiliate hospital) perceived that their readmission could have been avoided if either enhanced discharge instructions, a review of medicines, or follow-up with their primary care providers had occurred. Given the large patient demographic and liberal inclusion criteria of this study, it is unclear what (if any) issues related to the internal medicine population. The specific type of education that patients found to be lacking was unclear, however, Suffoletto et al. (2014) suggested that patients' perceptions of their discharge was important because readmissions are costly.



It seems, then, that it is necessary to have a fulsome understanding of causes of readmission from both healthcare providers and patients to determine how to improve patients' experiences and reduce burden on the healthcare system. Although the authors of the studies reviewed have described the overall types of concerns patients were experiencing (Howard-Anderson et al., 2016; Kommuri et al., 2012; Suffoletto et al., 2014), the transferability of these findings to inform policies and practices in a local context is limited because of a lack of specificity in the research process and generalizability of the findings.

In a Canadian qualitative descriptive study of eight internal medicine patients with multimorbidity, researchers cited insufficient discharge instructions as one of the top four reasons for readmission soon after discharge (Vat et al., 2015). The researchers did not define the readmission timeframe, referring to it only as "soon." They recommended healthcare professionals ought to ensure assessment of patients' understanding of their conditions and their readiness for self-management. The researchers argued that patients' views and input are vital in informing care and discharge practices. They stressed that all patient concerns should be heard and understood prior to discharge, thereby ensuring adequate discharge support. Despite the arguments of these researchers, whether patients experience "having their concerns heard and understood" as adequate discharge support is not known.

There is growing awareness that improved education as part of discharge practices can support successful patient transitions and prevent avoidable readmissions. The international literature shows that discharge education is a common theme in research with patients readmitted to acute care within a short period following discharge (Cakir et al., 2017; Flink & Ekstedt, 2017; Howard-Anderson et al., 2016; Kangovi et al., 2012; Kommuri et al., 2012; Suffoletto et al., 2014; Vat et al., 2015). However, research studies that capture a fuller, more specific

understanding of how patients experience their discharge education and the ways this might inform nursing practice for discharge education is lacking. Exploring patients' experiences can offer deeper insights into readmission. The study reported in this thesis thus addresses a gap that has local and broader utility, to inform understanding and practice for nurses in internal medicine contexts.

### **Patient Readiness for Discharge**

A second theme in the literature relates to patients' perspectives of being discharged from acute care too early. Vat et al. (2015) found that feeling they were discharged too soon was among the top four reasons why patients believed their transition home was unsuccessful. A similar finding was reported by Jeffs et al. (2014), who used an exploratory case design to investigate perspectives of discharge from patients, families, and healthcare professionals. Patients identified not feeling well enough to self-manage, feeling afraid of being unable to manage at home, and feeling functionally too deconditioned as root causes for readmission. The findings from this study seem important given the increasing average age of medical patients.

In addition to physical and functional concerns, lack of knowledge and understanding also matters to patients, leaving them feeling unprepared to leave hospital. Suffoletto et al. (2014) reported 27% to 44% of patients believed that readmission was unavoidable due to being discharged before they were ready. In a prospective observational study, researchers found that 90% of medical patients perceived a lack of readiness for discharge as a cause for readmission (Harrison et al., 2016). Specifically, they cited a lack of knowledge, pain, limitations in understanding treatment plans, as well as functional limitations as the most significant factors contributing to this perception.

The research suggests that exploring patients' sense of readiness to leave hospital can inform healthcare professionals' understanding about why patients are readmitted to acute care. The experiences that seem to inform individual readiness can include knowledge gaps, physical, psychological, emotional, and social issues. In practice, patients' felt sense of readiness is not a practical criterion for determining when discharge should happen. This is because the subjective feeling of being "ready" does not necessarily correspond with resourcing and timing issues that also influence decisions about discharge dates from inpatient care. Although readiness does not always align with other considerations for discharge, there remains a need for healthcare providers to ensure patients, family, and carers' perceptions are shared and understood (Stein et al., 2016; Suffoletto et al., 2014) to optimize discharge planning practices. For example, it may help to develop insights into individual, family, and system resilience, and ability to adapt to health transitions. Despite concern about the practicality of applying readiness to discharge criteria, in this current study, I will explore patients' perceptions and discuss them alongside findings of the existing literature.

### **Mental Health Issues and Social Support**

The literature suggests that mental health and broader social support and networks influence readmission of CCD patients. In a retrospective cohort study with 240 participants, Borkenhagen et al. (2017) found that patients who were frail and elderly were more likely to be readmitted to acute care within 30 days of discharge if they reported anxiety ( $p = .02$ ) or depression ( $p = .02$ ). Similar results were noted by Kangovi et al. (2012) who found that patients reported depressed mood and stress as significant barriers to transitioning successfully post discharge and that these were contributing factors to patients seeking readmission. Joynt and Jha (2012) offered that mental illness, and a lack of social support, were two of the most significant

and deep-seated issues common to patients who are readmitted. Patient perception of social support was also identified as a significant barrier in successful transition post-discharge (Cakir et al., 2017).

Mental health and social context need to be considered alongside other factors that influence experiences of readmission. Mercer et al. (2016) stated that “people with combined mental and physical health multimorbidity are at the at the highest risk of safety incidents” and need to be recognized “within the context of the person who suffers from them” (pp. 10-11). The argument from Mercer et al. suggests that discharge and readmission need to be understood as part of a complex, holistic picture rather than as simplified and discreet cause and effect phenomena. A search of literature in the PubMed database offered no research findings associated with the terms *internal medicine*, *readmission*, and *mental health*. Similarly, little information is known on how healthcare leaders/practitioners support mental health issues in patients with CCD and multimorbidity. Exploring this aspect of patients’ experiences is perhaps best undertaken in a way that explores and unpacks experiences to attend to a more holistic perspective.

### **Summary of Literature Review**

The literature offers some limited insights into reasons for readmission to acute internal medicine contexts. These insights are derived primarily from quantitative studies that do not offer sufficient insight into patients’ experiences. Where patients’ experiences have been sought, they have noted concerns about lack of discharge education, not feeling ready for discharge, and, to a lesser extent, mental health issues and issues with social support. The gaps that remain include a scarcity of Canadian research as well as a lack of research that focuses on patients who are readmitted to internal medicine contexts. Given the complexity of illness, treatment, and care

for this population, there is a need for research that explicitly addresses how internal medicine patients experience and make sense of readmissions to hospital within 30 days of their initial discharge home.

### **Chapter 3: Research Design**

In Chapter Two, I reviewed the literature and concluded that a study into the experiences of internal medicine patients who are readmitted within 30 days of discharge is warranted. The research question that was addressed in this study was: What are internal medicine patients' experiences of readmission? To enable exploration of patients' experiences, this study is a qualitative thematic analysis. In the study design, I draw upon theoretical perspectives derived from social constructivism and complexity theory. A thematic analysis method is used to analyze data and create themes that illustrate patients' experiences. The thematic analysis, which is presented in Chapter Four, forms the basis for later discussion and theorizing complexities associated with patient discharge and readmission.

#### **Methodological Dimensions of this Study**

Thematic analysis is a method of data analysis that can be shaped and guided by different methodological approaches (Braun & Clarke, 2013). A research methodology comprises the philosophical and theoretical dimensions of a study that serve to organize how to understand and engage with the research field. In this section, I set out the methodological dimensions of this study before turning to considerations of method and analysis.

Evidence for healthcare practice is dominated by objectivism, positivism, and empiricism. As a result of this dominance, many of the truths for practice in healthcare are "scientific" truths, derived from (preferably controlled) quantitative studies (Crotty, 1998; Rodgers, 2005). The benefits of medical advances derived from the scientific method are inestimable and have contributed immeasurably to the advancement of humankind. To date, this type of research has been the mainstay for examining readmission in internal medicine from a healthcare/medical perspective. Quantitative studies, however, have not been able to capture

human experiences associated with discharge and readmission. Where exposition of complex, holistic phenomena is sought, research that extends beyond questions of “does this cause that?” is needed.

### ***Social Constructivism***

This study is, thus, a study of experience in the context of healthcare. Experiences of health, illness, and responses to ill-health are social phenomena. Broadly speaking, in Western society, people live as individuals in a social world. In this way, experiences of health and illness and the practices that arise in response to illness are understood through interaction between individual and the social world in which they are situated.

Social constructivism is a theoretical perspective that attends to the ways that people come to know and experience. CCD involves many different experiences of self, other, and the social world, including experiences of healthcare. This multiplicity of factors suggests a multiplicity of experiences and, as such, the need for a social constructivist view.

Epistemologically, social constructivism implies knowing arises through engagement and relationships between people and the objects and phenomena of the social world (Crotty, 1998; Speziale et al., 2011)

One of the reasons to do qualitative research is to explore human experience. Constructivist qualitative research explores and derives knowledges from what is experienced, perceived, and felt, whereas quantitative research focuses more on what is observed (Rodgers, 2005; Speziale et al., 2011). Social constructivism aligns with the research question posed for this qualitative study because it focuses inquiry on the experience of patients who are readmitted back to internal medicine within 30 days of discharge from the point of view of the person who

experiences it. By inquiring in this way, patients' experiences become a valued site for deriving knowledge that can inform nursing practice.

### ***Complexity Theory***

The Canadian healthcare system is an intricate, evolving, and dynamic entity that has developed in response to a myriad of influences. The many social, political, economic, and disciplinary influences on healthcare systems means that the provision of healthcare is not a straightforward endeavour. Complexity theory is one way to explore systems that are characterized by non-linear and uncertain change (Grobman, 2005). Complexity theory explains how “relationships between members of [...] systems give rise to collective behaviour and sheds light on how a system interacts with its environment (Sammut-Bonnici, 2015, n. p.). The overall purpose of a complex system emerges from the unique interactions that occur between its members (Plsek & Greenhalgh, 2001). The purpose of a system is, thus, not predetermined, but rather emergent, even constructed, through the interactions that occur within it.

Complexity theory proposes that, within a complex adaptive system such as healthcare, there is an intricate web of interconnectedness and collaboration that occurs. A study informed by complexity theory thus shows connections and collaborations that occur within a system. In the context of this current study, complexity theory emphasizes that the knowledge, practices, and purpose of nurses—in relation to discharge and readmission in internal medicine—are not fixed. Instead, the presence of complexity allows for engagement with possibilities for practice that emerge through engaging in the social world of nursing practice in context. Complexity theory has been previously used to think about how healthcare has evolved and how it is delivered (Kannampallil et al., 2011; Leykum et al., 2007; Plsek & Greenhalgh, 2001; Tenbensel, 2013).



Within the context of internal medicine, patient recovery is supported through a collaborative model where optimal recovery cannot be attained without ongoing communication and collaboration between interdisciplinary team members. In the world of internal medicine, complexity theory challenges nurses to reconsider the value or relevance of reductionist approaches to patient care when patients' admissions are characterized by complexities, contradictions, complications, and inconsistencies. Sturmberg et al. (2016) stated that "the most important step in managing complexity is understanding that any issue is embedded in a particular context, that is, it is interdependent with other variables" (p. 427). Complexity theory is non-linear, and so applying it to practice challenges nurses to go beyond taken-for-granted perspectives on patients and practice and to look for new connections and interconnections of experiences, meaning, and practice; as Miles (2009) suggested, in internal medicine, the whole is greater than the sum of its parts and cannot be understood effectively as multiple linear processes. For this study, complexity theory is a call to remain open to new connections of meaning between the way the health system works, and how patients experience and respond to it, and in the analysis and interpretation of data.

Complexity is ubiquitous in internal medicine, yet it remains an evolving concept. Safford et al. (2007) stated that complexity becomes a barrier to attaining optimal health if it is not recognised. Furthermore, appreciation for a more evolved understanding of what complexity represents in internal medicine would support change in a healthcare system that is showing signs of being inflexible and "unaccommodating" (p. 387). While in acute care and after discharge, each person's experience is complex due to multi-morbidities and individual pathways for care within the healthcare system.

Researchers have found other ways complexity is manifested and recognized in internal medicine. Iglesias, et al. (2016) found regional coordination of care, as well as socioeconomic, cultural, environmental, and behavioral factors influenced complexity. Loeb et al. (2016) asserted that multimorbidity, characteristic of CCD, requires multifaceted treatment beyond medical considerations, to include psychosocial issues, health literacy, social support, financial needs, and caregiver needs. As multimorbidity increases, treatment in response to it becomes more complex. In consideration of this, social support of patients becomes increasingly significant (Ho et al., 2015). Tyack et al. (2016) posited complexity involves recognition of the effect multiple diseases have on people's ability to perform daily activities, their chronic pain considerations, psychological effects, as well as varying socio-economic status. Additionally, Tyack et al. found the specific number of comorbidities experienced by patients was significant in informing the overall impact of disease on patients with multimorbidity. Shippee et al. (2012) concurred adding complexity can have a cumulative impact where clinical and social issues interrelate. Treatment and illness difficulties serve as feedback loops, connecting negative consequences to further imbalances, such that complexity accumulates over time.

The picture of complexity in internal medicine patients shifts the emphasis for care from a primarily *disease-centered* approach to a *patient-centered* model (Ho et al., 2015). Patients experience complexity and are being treated in complex environments, in complex ways. For example, patients in internal medicine are advancing in age. Aging occurs alongside varying degrees of physical and psychological resilience, which in turn has implications for how patients experience and manage multimorbidity; this further affects how treatment regimens are directed within the healthcare system (Nardi et al., 2007). Patient-centered care provided in complex

internal medicine contexts must recognize treatment plans that consider patient needs, preferences, and motivation are necessary to achieve optimal health (Bayliss, et al., 2007).

## **Research Methods**

In this section, I outline the methods undertaken for this research. I begin by discussing the context for the research. I then describe the population and participant sample, data collection methods, and data analysis. In this section, I also address questions of rigor as well as the ethical dimensions of the research.

### ***Research Context***

This study was conducted on an internal medicine unit in a metropolitan hospital in Alberta, Canada. The choice to recruit at one site was both pragmatic and methodological. Internal medicine patients were the sole focus of the unit where I recruited participants. This meant that identifying and recruiting participants was able to be done efficiently. Although practices at all hospitals are guided by Alberta Health Service policy, there are cultural and practice differences between sites that might complicate analysis and interpretation of data. Recruiting at one site enabled a more focused exploration of complexity in relation to a system.

Prior to seeking institutional ethics approval (REB19-0298), the protocol (proposal) for this study was reviewed and approved by the section chief of general internal medicine and by the nurse manager of the unit where interviews were conducted. I met individually with nurses and administrative staff on the unit to discuss the study and clarify what they would be asked to do to assist with recruitment. These individual conversations were followed up with regular visits to the unit where I addressed general questions. I ensured my contact information was easily accessible to all involved to facilitate answering questions and for recruitment and data collection.

### ***Participants/Recruitment***

Participants for this study were a purposive sample of patients who had been discharged from internal medicine and readmitted back to the internal medicine acute care unit within 30 days of being discharged home. In total, 17 participants were recruited and interviewed. After consulting with the hospital information technology department, a computer-generated email notified me of potential participants on the internal medicine unit. Inclusion criteria for the study were participants who: (a) were readmitted to the acute care internal medicine setting within 30 days of discharge from an internal medicine setting within a metropolitan city in Alberta; (b) resided in the city<sup>2</sup>; (c) were at least 18 years of age; (d) fluent in English; (e) were able to consent to participate; and (f) returning to their private residences following discharge.

Patients who did not meet the inclusion criteria were excluded from the study. Thirty-day readmission is a common benchmark used in internal medicine in the literature and is used by the Canadian Institute for Health Information [CIHI] as well as the Centers for Medicare & Medicaid Services (CMS). Therefore, this standard was applied to this study. Local participants were sought to gain a sample of people living in a defined context that included the same levels of service and care upon discharge. Legal minors were not sought for this study given the context of recruitment being an adult internal medicine unit. Those who could not speak English were excluded because the cost of interviewers and translators was beyond the financial resources available to support this study. Any patient who was unable to provide consent to be interviewed was excluded. Finally, excluding patients who did not reside at private residences enabled research to be focused on those who had been assessed to be able to return to a level of

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<sup>2</sup> Participants were pre-screened by AHS, and I received details of eligible participants from their information technology department. One participant lived just outside of the city limits which did not become apparent until the interview was transcribed.

independence that did not require residing in long term care. Thus, the primary population of focus was internal medicine patients who had been discharged from the acute care internal medicine setting, yet, for reasons unknown, were not able to remain there, and therefore returned to internal medicine within 30 days of discharge.

Patient recruitment for the study was voluntary. Once the information technology department had identified potential participants, I approached the primary nurses of potential recruitment candidates to determine whether individuals were suitable. Suitability encompassed such things as medical stability, and other contextual factors that, from the primary nurse's perspective, might make their patients unsuitable. After determining patients were appropriate for interviewing, I provided each nurse with a summary script to read to the potential study candidate (Appendix B). The script included an overview of the purpose of the study. The script also clarified that neither the quality of their care, their healthcare team members, nor any aspect of their care plan would be influenced by whether they participated. Patients were not pressured, coerced, or persuaded to participate. After reading the script, primary nurses then asked potential study candidates if they would be willing to participate in the study. After agreeing verbally to participate, the primary nurses made me aware of the patient's agreement. It was at that time that I approached and introduced myself to participants, gave them more information about the study, clarified any questions, and obtained each participant's signed consent.

### ***Data Collection***

Data collection began in winter and concluded in the fall of 2020. Due to the COVID-19 outbreak, AHS paused non-essential research to limit the number of people entering the facility. For this reason, there was a 5-month suspension in data collection. Data comprised transcripts of semi-structured research interviews. Interviews lasted between twenty minutes and two hours

with the average range between 45 minutes and one hour. Interviews took place at the bedside as that was most conducive to patient safety, comfort, and privacy. Once I obtained informed consent and consent for the recording and transcribing of each interview, I guided study participants through a series of open- and closed-ended questions. The length of each interview varied dependent on participant preferences and engagement as well as their scheduling and healthcare needs. Once interviews were completed, I transcribed them verbatim and checked them for accuracy against the audio recordings.

### ***Data Analysis***

Data were analyzed using the qualitative thematic analysis approach outlined by Braun and Clarke (2006). The goal of thematic analysis is to capture participants' experiences and perspectives (Braun & Clarke, 2013). The value of using thematic analysis as a method for this qualitative study was that it required me to maintain focus on the participant; that is, patients' words and their recollections and descriptions of their readmission experience. Given that patients' experiences within and outside the health system are complex, thematic analysis offered a means to analyze experiences and make sense of them in a way that could show complexity within the manageable bounds of thematizing. Braun and Clarke (2013) stated that thematic analysis "is useful in identifying patterns within and across data in relation to participants' lived experience, views and perspectives, and behavior and practices; 'experiential' research which seeks to understand what participants' think, feel, and do" (p. 297). To accomplish this, I followed the six phases of analysis as recommended by Braun and Clarke (2006).

**Phase 1: Familiarization with the Data.** To begin the process of data analysis, I personally transcribed all interviews verbatim. This process was helpful because it required me to repeatedly listen to and consider all the data in its most raw state. Braun and Clarke (2006)

stressed that this phase of becoming fully engaged in the data facilitates a depth and breadth of the content that “provides the bedrock for the rest of the analysis” (p. 86). With this awareness, I familiarized myself with every word and every sentence as I repeatedly reviewed original audio recordings against the transcripts to ensure they were documented accurately. Once transcriptions were completed, I continued to read and re-read data as I contemplated and considered my overall impressions. I wrote comments on my initial impressions within the transcripts using Microsoft Word’s “comment” feature. I also discussed these notes along with my overall impressions with my supervisor on a regular basis to become comfortable conversing with and about the data.

**Phase 2: Generating Initial Codes.** Once initial transcripts were completed, the process of generating initial codes began (Braun & Clarke, 2006). Line by line, I methodically appraised and assessed the data corpus to form initial codes. I searched word by word, giving full attention to each line, looking for interesting aspects of the data based on what stood out as interesting or thematic across the data (Braun & Clarke, 2006, p. 87). For example, the first code I identified was self-determination and personal responsibility based on locating words and phrases that reflected these attributes. As I assessed each line of the data, I highlighted words and statements that reflected this code throughout each transcript. As I repeatedly read and re-read the data, multiple codes were identified and highlighted using a color-coding scheme.

**Phase 3: Searching for Themes.** After systematically highlighting multiple codes throughout the data, I analyzed them in broader terms. I formulated potential themes and documented them on a thematic map (Appendix E), which is a table that allowed for the added benefit of a visual representation of the data. I continued to analyze the themes I had formulated in relation to the codes that were copied into the map from the transcripts. With this visual

representation, I began to appreciate broader, overarching themes in the data. For example, as I analyzed and considered codes from across the data for “self-determination/personal responsibility,” I noticed that study participants through these codes shared a common tendency to situate themselves as *partners* in their healthcare. Therefore, the sub-theme “patient as partner” was created. As the process continued, additional sub-themes were created and repeatedly analyzed and considered in relation to the data to ensure they accurately represented the codes. As the analysis continued, and codes and emerging themes was analyzed and re-analyzed, the initial draft of the thematic map was completed. I met with my supervisor to discuss the initial map and then with my thesis committee to further discuss the analysis. Using the feedback provided, I continued to refine my thematic map.

**Phase 4: Reviewing Themes.** At this stage, my initial thematic analysis map was completed, however ongoing refinement was needed. Braun and Clarke (2006) cited two levels of review at this stage. The first involved me, once again, reviewing all the coded data for each theme, paying specific attention to whether the codes formed a consistent and intelligible pattern. Once this was confirmed, I proceeded to the second level of review. At this stage, I critically reconsidered whether the codes I had generated fully aligned with the associated themes. I reassessed the entire data set to confirm whether my themes fully aligned and represented the data as a whole (Braun & Clarke, 2006, p. 90). It was at this stage, that I identified that one of the themes did not quite represent the codes in specific enough terms. Therefore, I reconsidered the codes and determined a more accurately worded theme, improving the congruence of how the codes informed the theme. Further minor refinements were made as the process of critically analyzing the data progressed and further meetings to discuss these considerations with my thesis supervisor continued. After critically re-examining my thematic map against the data set multiple



times, I arrived at a point where I could no longer find inaccuracies or misalignments and proceeded to the next phase.

**Phase 5: Defining and Naming Themes.** At this stage of the thematic analysis, I had already devised a set of overarching themes but needed to continue the process of ensuring that the themes and sub-themes generated were truly representative of coded data. To accomplish this, I read, and re-read the transcripts. Once the transcripts were reviewed to confirm that the codes generated were all color-coded accurately, I read and re-read the codes to ensure they all aligned with the sub-themes. Once this was confirmed, I read and re-read the sub-themes in careful consideration to the given overarching themes to ensure their congruence. During this phase, I also discussed my codes, sub-themes, and themes with my supervisor and committee. Additionally, during this stage, I provided my committee a summary of my codes, sub-themes, and overarching themes. This was incredibly valuable as their questions prompted me to further consider what I meant by the wording of my codes, sub-themes, and overarching themes. Upon completion of defining and naming themes was confirmed, I began the process of “define and refine” (Braun and Clarke, 2006, p. 90) by writing my discussion. Through this process, I continued to critically analyze what my themes, sub-themes, and codes specifically depicted and developed a discussion that captured the essence of what each theme represented.

**Phase 6: Producing the Report.** The final phase of a thematic analysis is producing a written report that accurately and descriptively captures the experiences of study participants in relation to the research question (Braun and Clark, 2006). This thesis is that report, integrating the perspectives of study participants further contributing to, and shaping what is known in the literature about internal medicine patient’s experiences of readmission within 30 days of being discharged from the acute care, internal medicine setting.

## **Rigour**

Rigour for this method of qualitative data analysis was achieved through diligent attention to the steps of analysis outlined by Braun and Clarke (2006). The process for coding thematic analysis correctly involved a commitment to systematically assessing data from a broad and narrow lens. It required dedication to reading and re-reading data so that the analysis conformed to methodologically robust standards. In addition, I consulted with my supervisor and committee to openly discuss my process through Braun and Clarke's (2006) steps, and to review codes, sub-themes, and themes as they were developing.

In relation to the trustworthiness of the research, I attended to Lincoln and Guba's (1985) criteria, which are commonly cited in qualitative research. These criteria are a) credibility, b) dependability, c) confirmability, and d) transferability. I also read Forero et al. (2018), who proposed strategies for practical application of Lincoln and Guba's criteria.

## ***Credibility***

Forero et al. (2018) stated that credibility is supported when researchers have a breadth and depth of knowledge about the research protocol they are using. This includes such things as background information about the research and a strong familiarity with the setting in which it takes place. With this information, researchers can optimally appreciate the theory and context related to their research to optimally understand the participant feedback they receive. This in turn supports the researcher to produce an accurate representation of participants' experiences.

I am familiar with the theoretical background of this study from my experience as an internal medicine nurse as well as being a graduate student researching patients' experiences of readmission. Furthermore, I was familiar with the unit, its staff, and overall standards of practice

through my work as a registered nurse. With this background, I was able to quickly understand participants' responses to questions about their experiences of discharge and readmission.

Credibility is enhanced when participants in a study can recognize their experiences in the reporting of the study (Lincoln & Guba, 1985). This perspective from participants is taken to be a kind of validity in that the researcher has produced findings that are recognizable to those who provided the data and that resonant with their experiences. Although I was able to receive affirmation from my supervisor and committee that my analysis was faithful to the data, I was not able to complete any member checking for credibility directly with participants. This was due to constraints with timing for data collection, transcription, and analysis alongside patients' length of admission.

The credibility of this study was greatly reliant on my ability to interview participants effectively and document the data obtained from interviews accurately. The total number of interviews conducted for this study was 17, despite signs of data saturation well in advance of this. I found that in the early interviews, I was struggling to ask questions in a way that encouraged patients to respond with depth rather than brief answers. I found myself to be less comfortable in my ability to engage with participants, and in my confidence in taking opportunities beyond my interview questions to explore participant responses. There was a tendency towards *getting answers* to interview questions rather than encouraging participants to *explore their answers*. I discussed interview techniques with my supervisor and then implemented these when I was able to return to complete interviews after COVID restrictions were lifted. I noticed that this seemed to enhance the quality of my relational experiences and communication strategies with participants.

Over the course of data collection, interviews got longer because I became more comfortable with asking questions that encouraged participants to explore experience. I also spent considerable time reflecting on the interviews themselves. Lincoln and Guba (1985) recommended peer debriefing as a strategy to support credibility, which I found to be incredibly helpful during this phase. Although I did not debrief directly with registered nurse peers, I met with my supervisor for regular reflection and debriefing. It was in these meetings that I was able to refine my interviewing questions and communication style with each interview and thus enhance the quality of data generated. I came to experience that while data saturation remained, I felt a stronger sense of confidence in knowing I had afforded participants opportunities to explore their perspectives in a more exploratory way.

### ***Dependability***

Dependability of qualitative research is achieved through a detailed account of the study protocol and an audit trail (Lincoln & Guba, 1985). This chapter contains a detailed description of the conduct of this research. This thesis also offers an audit trail for the research procedure, including documentation and rationale for key decisions that were made. This thesis contains evidence of original data, and the analysis and discussion are closely linked to the data and themes derived from it. Description of the analytic process is provided to enable another researcher to follow the same procedures. Key artefacts of the research process are attached as appendices to this thesis to further ensure that a robust audit trail is present. Once data collection and analysis were complete, a coded copy of all interview transcripts along with participants' consent forms were sent to my supervisor for secure storage and so they can be accessed and reviewed if required.

### ***Confirmability***

Confirmability refers to the likelihood that if the study data were analyzed by another researcher, the results would corroborate original findings (Lincoln & Guba, 1985). Therefore, this thesis contains the necessary information to enable another researcher to replicate this study.

**Reflexivity.** In qualitative research, reflexivity refers to a “researcher’s ability to be able to self-consciously refer to him or herself in relation to the production of knowledge” within a research study (Roulston, 2010, p. 116). For this study to be evaluated by someone outside of the research it is, therefore, necessary for me to be transparent about my own decision making and conduct in relation to the study. Personal reflection was integral throughout this study, and it was through reflection that I considered my values, experiences, and pre-existing beliefs in relation to my role as researcher. I have been clear that I am an internal medicine registered nurse and, as such, I brought my practice knowledge and experiences with me into this research. My background has been both beneficial and limiting in different ways.

As a practicing registered nurse, I am experienced in interviewing patients for the purpose of formulating clinical assessments. I expected a research interview to be a similar experience, but it was not. I became quickly aware that I was not confident in carrying out an exploratory interview. I found myself quite ill at ease with the sense of not really knowing why. As I reflected on my discomfort, I realised that I was uncomfortable because what participants were saying in interviews was not congruent with what I had experienced as an internal medicine nurse; it was not what I expected to hear. This realization of the influence of my personal biases was an important turning point for me. It helped me to let go of some of my expectations and to be more open to hearing what participants had to say. It also allowed me to be more open to the possibilities for understanding as I ventured into and worked through the steps of data analysis.

### ***Transferability***

Transferability of thematic analysis research reflects the degree to which the results can be applied to other contexts or settings (Lincoln & Guba, 1985). To attend to this criterion, I recruited a purposive sample of internal medicine patients as the best source of data. Reaching data saturation improves confidence that important aspects of patients' experiences have not been missed (Bowen, 2008). In Chapter Four, I have provided a detailed description of the thematic analysis. Chapter Five presents a discussion based on the findings of the study. In this Chapter I have been careful to conclude and make recommendations within the confines of the study method and data. These approaches can help other researchers and clinicians to determine if the findings of this study could be applied to similar contexts.

### **Ethical Considerations for this Study**

The study was granted ethics approval from the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary (REB19-0298). I ensured written, informed consent was obtained from all study participants. Potential participants received an explanation of the purpose of the study, what they would be asked to do, risks, and confidentiality. Patients were informed they were not obligated in any way to participate in the study and that their medical treatment would remain to the same standard regardless of participation. Efforts were taken to ensure patients would not feel coerced to participate. Participants' confidentiality was protected through safe storage of hard and electronic copies of data as well as the separation of identifying information from research transcripts. To de-identify transcripts, each transcript was given a number and participants were given a pseudonym in place of their real names. In this thesis, participants are referred to by their transcript number.

While the risks associated with this study were few, they did exist. Given the nature of the range of diagnoses treated in internal medicine contexts, it was possible that participants could be generally fatigued, become fatigued during the interview, or may otherwise not feel well. Participants were informed they could pause and resume the interview or schedule the interview for another time if they felt unable to continue or participate. Internal medicine patients often live with many health-related and social complexities, risk factors, and with the knowledge of a poor prognosis. Given that interview questions focused on participants' experiences and perspectives, I was aware the conversations could be stressful or add to anxiety or worry. To minimize risks and discomforts, as well as mitigate harm, I consulted with the primary RN in charge of each participant's care prior to conducting all interviews to ensure that it was appropriate for potential participants to be interviewed. Appropriateness was determined by the RNs assessment and considerations of medical acuity and whether individual patients were confused/competent. After determining potential participants were appropriate for interviewing, they were first approached by their primary nurses who read a script (Appendix E) to describe the purpose of the study. Once verbal consent was obtained, I introduced myself to participants and again reviewed the purpose of the study. Once I received verbal agreement, I obtained their signed consent. At the beginning of the interviews, I informed participants about the types of questions I would be asking and that they could decline to respond to any questions.

## **Chapter Summary**

The literature review shows a gap in the internal medicine literature: patients' perspectives on readmission following previous discharge. This study, informed by social constructivist and complexity theory offers nurses, other healthcare practitioners, healthcare leaders, and other stakeholders the opportunity to explore this different dimension of the issue.

Although there is some limited qualitative insight in the literature, the influence of factors such as population characteristics, government funding, health system structure and healthcare insurance mean patients' experiences in the existing literature may not well inform local practices in Alberta. This qualitative thematic analysis offers a means to explore experiences in a way that can contribute to local understanding and practice.



## Chapter 4: Data Analysis

In this chapter, I present a thematic analysis that addresses the question for this research: What are internal medicine patients' experiences of readmission? The data collected revealed participants experienced various types of complications and challenges that are not easily resolved. The data also showed how navigating life with CCD was, for most participants, very involved and characterized by numerous complexities. From analysis of the data, three themes emerged: *Life with Medical Complexity is Complicated*, *Relationships Matter*, and *Specialized Care is Needed*. Each theme contains sub themes that further illustrate participants' experiences within the theme.

Table 1:

### *Thematic Analysis Map*

Theme	Sub-theme	Codes
Life with Medical Complexity is Complicated	Chronic Complex Disease is Continually Changing	Disease is Progressive and Becomes More Complex, Suddenly..., Multiplicity
	Negotiating and Adapting to Changes in Social and Familial Spaces	Relationships are Impacted
	The Healthcare System is Complex	The System is Responsive
Relationships Matter	Patient as Partner	Self-Determination/Personal Responsibility
	Provider Relationships	Effective Interaction with Healthcare Providers, Positive Engagement with Healthcare Providers
Specialized Care is Needed	A Circuitous Route	A Supervised Tipping Point, Multiples in Acute Care...
	Readmission is Unavoidable	Always in the System

### **Theme 1: Life with Medical Complexity is Complicated**

Life with Medical Complexity is Complicated reveals the principal components that inform and affect acute illness as experienced by internal medicine patients in this study. All

participants spoke about a depth and range of experiences that give insight into the ways that life with medical complexity is complicated. Participants described how numerous aspects of experience influence and potentiate medical complexity in an interconnected and ever-changing way. For example, participant 8 described the elusiveness of balance and the awareness that regulating the trajectory of one disease process is often influenced by the progression of concurrent disease processes, the treatment of which was often dependent on such things as laboratory and diagnostic imaging studies. As a result of these kinds of complexities, illness management continually changed for him:

*I'm on, well, ah, 4 pages of meds and they all conflict with one another. So, umm, I have a, I have an itch as a result of this bile duct not working properly, and it's all over my body, and I take Rifampin and that interacts with a lot of the other drugs I'm taking. So, it's a delicate balance as to which drugs I am given when, and at what dosages and stuff. So, ah, and so a lot of times ah, they sort of get, I mean, the doctors get the pain away, but my blood levels are down, right, so they keep me in until they're right. Right now, my potassium was too high, so they reduced it. Now they're looking into finding out what this pain is. So, it's a complicated situation, yes.*

In CCD, where multiple organs are affected, treatment options need to be considered alongside other treatments. Patients can experience effects and side-effects of multiple medications that compound complexity.

Data revealed participants in this study anticipated medical symptoms to be fluid, elusive, and unpredictable. Fifteen of the 17 participants believed their readmissions could not have been avoided and lived with the expectation that unforeseen complications might arise. The experience of living with medical complexity was an intrinsic part of daily life requiring constant

attention and regular collaboration with a range of healthcare professionals. Participants spoke about their experiences in a way that implied chronicity was so embedded in life experiences that it was not just a part of life; it *was* life. Participant 8 described:

*It's just one day at a time, one step at a time. I come into the hospital for a, for something and sometimes I'm supposed to be like "in and out" or "in one day and out the next" and so far, it's been at least a week, and in some cases, months before I leave.*

Participant 15's description captured chronicity a little differently when he stated,

*but it is a long process getting there (referring to liver transplant). Cause I had how many infusions of blood? My hemoglobin would go down to 40. My routine was, Monday go get blood work, Tuesday go get an infusion, transfusion. The next day, or if not, the same day do a scope, start it all over again on Wednesday.*

The journey of organ transplant for participants 8 and 15 began long before and continued long after their transplant surgery. Both experienced complications that had no straightforward solutions; for both, complexity led to further complexity.

Life with Medical Complexity is Complicated contains three subthemes that offer further insights into how complexity was experienced by participants in this study. The subthemes are (a) *Chronic Complex Disease is Continually Changing*, (b) *Negotiating and Adapting to Changes in Social and Familial Spaces*, and (c) *The Healthcare System is Complex*.

### ***Chronic Complex Disease is Continually Changing***

For participants in this study, CCD was continually changing. Change added its own form of complexity because when things were constantly in a state of flux, it was difficult, if not impossible, for participants to anticipate the trajectory of change. For example, new or evolving symptoms could be reflective of new or evolving disease process(es). For some participants,

their current symptoms were like those they had experienced in the past, but this was not the case for others. Participant 8, who had undergone a liver transplant, had a stent inserted into the right lobe of his liver during his previous admission to internal medicine. He was discharged home with the stent in-situ and experienced a change in symptoms that prompted him to seek reassessment:

*The doctor hasn't come to a conclusion yet as to what it is. The surgery pain went away. They gave me painkillers, and I, about four days later that I didn't need them anymore because that pain had gone ....and then after that I started getting gas buildup in my stomach or in my abdomen area and it, it usually goes away. But it, ah, the first time it did but this time it wasn't. And it gradually got worse and got to the point that it was very painful and that's why I came right here.*

The continuation of old symptoms as well as noticing new symptoms was a source of worry for participants that led to readmission and added to the complexity of their experience in this circumstance.

Acute medical complexity is common among the internal medicine patient population. Acute complexity might be associated with a single disease process or diagnosis or as part of multimorbidity. At times, participants described being reconciled to a lack of control over medical deteriorations, suggesting that it was part of their process. For many participants, the experience seemed to be that one thing leads to another, or that one aspect of their medical complexity layers onto another. Participant 9 said,

*Oh, my electrolytes were all messed up, so my sodium was low, and my potassium was getting high and so I was dizzy and lightheaded and unstable on my feet and a little confused.*

Participant 17 described the fluctuations and layers of complexity a little differently when she stated,

*Ok, I do have chronic low sodium. I'm also Type 1 Diabetic for 58 years, and then also Celiac, and there's a lot of different complications. You treat one thing; it will screw up something else. Umm, yeah, and so I came in May. I knew I had low sodium 'cause I can feel it. Now my gastrointestinal doctor has come up with a diagnosis of SIBO.*

These quotes illustrate that the experience of one thing leading to another is more than a simple cause and effect “this leads to that” relationship. Rather, the experience is one of knowing that constant change involves cascading, intersecting problems associated with diagnoses and conditions and interventions associated with them.

Medical deteriorations seemed to occur as an expected part of life for many participants. Participants described how these fluctuations were not always able to be controlled, either by them or their healthcare providers. As participant 9 stated, there were,

*Too many mitigating circumstances out of my control for me to be totally happy with my level of control when I go home ... Well, depends on how much water I drink and, how much Lasix I'm on, and last time they had me on too much Lasix and then just continued to wash my system out.*

Participant 9 was frustrated that there was no straightforward answer to his CCD. He was frustrated that his physicians were unable to offer lasting, definitive solutions that would increase his sense of control. Instead, his health needs were addressed in a more reactionary way; that is to say, as a response once unforeseen or unknowable complexities had occurred.

Participants described experiencing illness and its implications on how they lived life in various ways, but what most participants had in common was the sense that changes in

symptoms was common and that, over time, things became more complicated. All participants in this study experienced or were currently experiencing a progression of their condition(s), and readmissions reflected heightened complexity due to the advancement of disease processes or the treatment modalities required to become medically stabilized.

**Disease is Progressive and Becomes More Complex.** Participants 4, 5, 8, and 15 were previous organ transplant recipients who encountered medical complexity prior to and after their transplants. Participant 8 was aware that, while his doctors knew much about his current health challenges, his current experience of declining health also showed him that “a lot of stuff is unknown to the doctors.” Participant 8 explained:

*It's an unusual situation because normally you get a liver transplant and once you get the transplant you know, after a few months you get back to normal, and mine, that didn't happen to me. What happened was the bile ducts of the donor and my bile ducts were two different sizes and ah, so they had to put a stent in. Well, I went through several stents, and they never did find one that actually worked. And then they discovered that the bile ducts were blocking in the liver itself, and that's the reason why I have tubes put in. And the idea is to ah, strengthen the ah, the ah the bile duct in the liver so that they're strong enough, they're big enough to let the flow through and eventually the tubes will go away, will be taken out, and I'll have a normal bile duct and a liver that will work normally and ah, if that doesn't work, I am due for a second transplant.*

Participant 8 described a circumstance where one complexity, such as having a transplant, confers potential vulnerability to further complexity.

Participant 4 described her feelings of vulnerability as she reflected on the year since her transplant surgery. For her, progressive complexity was captured in the susceptibility of her immunity since her transplant:

*I catch everything. It doesn't matter. We don't do crowds. But it doesn't matter if we don't do crowds. You could come to my place as a "hello, how are you doing?" I might catch something from you.*

Participant 4 went on to describe emerging signs of deterioration in her health with newly diagnosed heart issues. She questioned whether her chemotherapy could have “triggered it” and concluded “I am vulnerable.” This statement seemed to have layers of meaning as I experienced this moment with participant 4. A feeling of vulnerability arose for her amid the unfolding complexity of life with medical complexity. Participant 4’s feelings of vulnerability encompassed the accumulating effects of medical complexity and the implications this was having on the way she experienced daily life, suggesting complexity was increasingly not just one aspect of life, but was life.

Whereas participant 4 was looking ahead towards vulnerability, participant 5 was further along in her illness and weary from her condition. The progression of chronic conditions contributed to participant 5’s weariness. She described a long-standing history of primary biliary cirrhosis that necessitated a liver transplant “15 – 20 years ago.” She further stated, “they have charts this high from the floor on me here, since 1982.” Since that time, she attended appointments with her hepatologist approximately every two to three months. She recalled that five years ago her liver “failed” noting, “I am very lucky to be alive”. Participant 5 discussed the chronic complexities of no longer having the option of a second liver transplant. She talked about how she continued to live with the underlying disease that caused her original liver to fail and

that continued to progressively cause her transplanted liver to fail. She also spoke about progressive kidney complications and understood the chronic nature of fluid shifts related to her ongoing liver and kidney conditions. She noted how she had experienced progressive fluid accumulation in her legs within just two days of returning home from her previous admission. During the time in between her discharge and readmission, participant 5 had undergone a paracentesis. As part of her daily experience with CCD, she described ongoing arthritic pain in both hips as well as persistent back pain. She spoke about how managing concurrent health challenges amid ongoing issues with insomnia made many days less productive and pleasant. As she encountered her most recent complication of debilitating, painful edema and associated infections, she expressed relief in knowing she would be cared for and attended to during her hospital stay. She further reflected that while dialysis was offered as a potential treatment option during this acute care admission, she had declined.

Throughout the interview, it was evident there was an associated mental toll for participant 5. She was living with complex, chronic disease that had a cumulative effect; she depicted the ongoing experience of life with chronicity as one where she had to “fight.” She recounted “fighting” in the context of the arduous day-to-day living with years of chronic disease and feeling weary. Yet, as the conversation ended, participant 5 seemed resolved to continue her fight even in the face of a shift in focus of care to palliation measures. As she considered the future, she said “...but I’m getting better. I know I’m getting there – I feel I’m getting better.” With years of experience of fighting medical complexity behind her, it seemed participant 5’s resolve remained steadfast, and I could not help but wonder if this comment reflected denial or whether participant 5 did not know how to not fight or be anything but determined. There are opportunities in moments like this for nurses to support patients’ resilience or determination in



ways that acknowledge and value their inner resources and to support transitions from a focus of fighting against medical complexity towards validating experience.

Participant 10, like participant 5, was also entering the palliative phase of her treatment. She described her most recent health decline as being punctuated with heightened anxiety alongside increasing breathlessness, chest pain, dizziness, nausea, and pain. After being readmitted to internal medicine, she was processing the news that her cancer, that she was aware had progressed during her last admission, was the cause of her health deterioration. When given the news she decided, “I’m not gonna do anything.” Instead, participant 10 opted for symptom management and comfort care.

For participant 12, there were multiple layers of complexity and intense emotion associated with her experience of progressive disease. After contracting a severe case of COVID-19 in addition to having maple syrup urine disease (MSUD), participant 12 was encountering acute on chronic gastro-intestinal issues, necessitating the need for oxygen, intravenous (IV) fluids and total parenteral nutrition (TPN). She described how her sense of progress could be short lived. While she might perceive progress on one day, this could become a setback the next day, but for no clear reason:

*My maple syrup urine disease combined with COVID is a bad combo. So, they have to treat one thing before they can get to the next. So, they have to treat maple syrup disease before they can help me with the COVID. They’re trying to figure out what’s going on with my body and why I have what I have. Because yesterday I had diarrhea five times. It was horrible cause the day before it, everything was fine, and then all of a sudden, I started just getting diarrhea again. Which is what happened before I came in on Thursday. It stopped for like a day and then I started getting it again.*

For participant 12, despite her desire for her medical complexity to resolve, recovery was not a straightforward process. Recovery involved numerous complexities and inconsistent progress which required her to look ahead one step at a time, one day at a time.

After years of medical complexity, life continued to unfold for participant 15 with new and developing complexities. Ever-changing disease processes were integral to life in the years prior to his liver transplant in 2011, and changes continued to define how he experienced life afterwards. After being readmitted to internal medicine with suspected ascending cholangitis and complications from central edema, participant 15 described a vast experience with CCD. He had numerous admissions over many years related to disease progression and complexity. In the years since his liver transplant, participant 15 encountered “flare ups in the bile duct,” bouts of depression, hip surgery twice, and prostate cancer. In the months prior to his current admission, he had undergone cryotherapy, brachytherapy, and 23 radiation treatments.

Each participant in this study outlined a personal journey through acute and chronic phases of illness(es). The data suggests that living with ever changing disease processes becomes an ongoing complexity that evolves from being *experienced as one aspect of life*, towards *life as it is lived every day*. For participants in this study, acute illness alone or in the context of multimorbidity could not be left unattended because complexities would only accumulate and intensify.

After disregarding symptoms, participant 1 described further illness and deepening complexity. Participant 1 had chronic obstructive pulmonary disease (COPD), atrial fibrillation, and history of myocardial infarction. In the context of his chronic conditions, participant 1 experienced his post-discharge decline as both a surprise and as a lesson to himself that his medical issues would not simply subside on their own. He described “ignoring symptoms” in the

months before and during his first admission, as well as feeling eager to be discharged from acute care to such an extent that he did everything he could to make the interdisciplinary team think he was ready to go home. He described purposely not relaying concerning symptoms in the hopes they would improve on their own after discharge:

*I thought, you know, I would pick up a bit but instead I got worse. And then it got to the point where I could hardly breathe. I was gasping like a fish. And uh, so, uh, we called the ambulance and uh they and brought me back and gave me, then they gave me more blood. So, so, I've been getting better and now I realize that this isn't just something that's just gonna cease. So, I, ah, changed my attitude. Now I am in it for the long-haul, whatever it takes. And, and ah, I'm gonna do it right.*

Participant 1's health worsened, and his medical issues became increasingly more complex because he was ignoring symptoms. His comments revealed the presence of some inner resources and personal attributes that could support his recovery and optimal health trajectory. In reflection, he recognized the need to actively engage in his healthcare to ensure his health issues were as manageable as possible.

Acute medical illness, alone or in the context of CCD was in a constant state of flux for participants in this study. It is within this flux that disease is fought and where symptoms are managed so that optimal quality of life can be realized. Participants shared the perspective that self-monitoring was necessary and that subtle or overt changes in symptoms needed prompt attention.

**Suddenly...** In the data analysis, I noticed how participants described some illness-related experiences in a way that implied they were either unexpected or happened very quickly. Over half of all participants in this study experienced a precipitous deterioration and symptoms

that necessitated urgent emergency care. Participants who encountered sudden deterioration commonly expressed emotions of suffering, urgency, fear, vulnerability, or perceived lack of control. Considering the context of chronic disease and that participants were likely educated about and familiar with what was happening to them, noticing the expression of *suddenly* was a somewhat unexpected moment in data analysis. While participants seemed comfortable and voiced confidence with their level of knowledge around their conditions, they did anticipate that changes were likely and reflected on their sense of sudden deterioration.

After a long-standing history of brittle diabetes, liver disease, and a recent diagnosis of seizure disorder, participant 2 described her sudden deterioration as an inevitability. She alluded to a perceived lack of control in preventing medical deterioration. She spoke with the expectation that this was a relatively normal aspect of her life, stating,

*When I get sick, I get sick fast, and then I end up going into diabetic ketoacidosis really easily, which we've been really working on, and it's been going a lot better since last September" ... It's just my body couldn't fight.*

She further explained, "once I get to that emergency state, I need to be right here...." Even as an inpatient in the internal medicine setting, participant 2 experienced a sudden, unforeseen deterioration of unstable hyperglycemia in the middle of the night after her diabetic ketoacidosis was medically stabilized. While reflecting on years of medical deteriorations, participant 2 noted from a broader standpoint that her readmission trends were occurring less frequently over time:

*It's not every month; it's every three months which is getting better. It's been about, it'll be five-bout five years in April since I've been coming back. I had a coma five years ago, and I've been here a lot since then.*

The experience of sudden post-discharge deterioration was notably *not* perceived by participant 7 who recalled feeling “fine,” unaware of any subjective signs of medical deterioration. She recalled within a matter of hours after having pre-arranged lab work drawn, she received a phone call from her general practitioner (GP) with the direction she be assessed at the (GP’s) office. After a few days of being closely monitored as an outpatient, she was directed to return to acute care. It was only after admission to the internal medicine unit that she recalled, “everything just went, went south” and symptoms became suddenly worse.

Unanticipated decline was also experienced by participant 11 who described feeling “surprised” to encounter progressive shortness of breath and increasing lack of tolerance to lying back in bed. She said, “I was fine for a few weeks and then all of a sudden it just hit again.” On arrival back to acute care, she learned fluid had re-accumulated around her lungs. She underwent a repeat thoracentesis, which found more fluid had accumulated compared to her first admission. Participant 11 said the plan after her initial admission was for a repeat computed tomography (CT) scan of her lungs as an outpatient to monitor the progression of her illness; her shortness of breath and precipitous deterioration occurred prior to having the prescribed outpatient CT scan completed.

After undergoing heart valve replacement surgery, participant 13 described having no memory of his experience of sudden deterioration of health. He recalled the first three days home from the hospital when he experienced “feeling like it was all working out alright.” He felt comfortable with all post-discharge instructions and took all prescribed medications (including antibiotics and anticoagulants) as ordered and completed recommended breathing exercises as directed. He described feel “well” and was eating and drinking and took regular walks with his wife. Participant 13 described how his wife and son noticed a sudden onset of confusion and they

called for an ambulance. His next memory was of being in the hospital three days after readmission, learning he had suffered multiple blood clots and platelet abnormalities.

Most participants of this study experienced deteriorations in their health that were perceived as sudden occurrences. While the data do not reveal the exact nature of worsening symptoms, they shed light on the perception of how many participants experienced sudden deteriorations in health that led to readmission back to acute care.

**Multiplicity.** The code of multiplicity reflects the occurrence of multiple contextual stressors that were occurring along with medical complexity for participants in this study. Within the context of all interviews, it became clear that participants shared similar but different experiences with extraneous stressors in their lives that added to, and even potentiated the stress of medical deterioration and readmission to acute care. Extraneous stress, while varied, became influential in the overall experience of how medical complexity was felt and added to the complexity of day-to-day life for most participants.

Participant 1 described his multiplicities and the “magnitude” and “persistence” of his recent health deterioration. Participant 1 reflected on the “trauma” he and his wife were experiencing as they moved out of the home they had lived in for over forty years. He stated “... it was a bigger ordeal than I realized.” While the move was a positive step to a more conducive living space, it marked a transition that appeared to be deeply felt by participant 1, the impact of which he had underestimated both physically and emotionally.

Multiplicities for participant 6 were also deeply felt and stemmed from overwhelming fear associated with managing his continuous positive airway pressure (CPAP) machine. The gravity of his fear was palpable as he described transitioning home:

*When I got home I, I, I, guess I'd sort of gotten used to the, the little thing that they put on you when they do your blood pressure to get, read your oxygen stats and things like that. Ah, that, that's probably what scared me most. I, a lot of times, I thought, you know, maybe I'm gonna go to bed tonight and not wake up because I do have sleep apnea and I, I do have a CPAP machine, but I don't always use it. I know I should, but I don't. And ahh, keeping the machine clean has been a terrible problem for me. But I, I, I am slowly overcoming it and, but it's, it's a slow process it's just, it's just one of those things, ah, I worry about a lot is being, getting into a situation where I can't catch my breath or whatever and, ah, collapsing or whatever. You know, I don't, I haven't collapsed per se for a long time since, probably since my stroke, but I... I worry about it.*

Participant 6's fears were such that he found what was happening to him difficult to understand and difficult to manage.

Participant 7 also experienced multiplicities as overwhelming at times. She cried as she reflected on the turmoil in her life. Negotiating the stress of divorce and transitioning to life in a different city was occurring amid an acute medical deterioration, the pathology of which was not yet understood. While experiencing acute illness, participant 7 described ongoing responsibilities she needed to negotiate as her mother's primary caregiver. While struggling with her own self-care, participant 7 also noted her daughter was not able to offer a lot of additional support because she was a new mom to twins. It was moving for me to be present with participant 7 as she reflected on her experiences. Her body was covered in severe and widespread welts, burns, swelling, chaffing, infection, and peripheral ischemia. As she cried, it was impossible to miss the intensity of her suffering both physically and emotionally:

*Well, not as much because they didn't know really what was going on at that point. They were just sort of frantically "OK will send it through ultrasound" And then they took off a litre and a half of fluid off my, my stomach. And I've got bleeding ulcers and I'm going through a really terrible divorce. So, this is (begins to cry), his hasn't helped and, um, anyway, He (meaning her ex-husband) knows nothing about it, and I want it to be that way. So yeah, everything was just kind of chaos if I could call it that, and that's when I had to trust them (healthcare team). Now the third time through it's like "okay, this is obviously a reaction to something they've given me". Pretty easy but let's go back see what's been given then that was easy to figure out. So, they, they knew, right? They had a point—the start point—and yeah now this one's [hospital admission] been really good.*

Participant 7's experience show how multiplicities are more than medical complexity.

Multiplicity involves layering of complexities. Although participant 7 experienced acute medical complexity, her multiplicities were her medical issues layered on relational and familial problems.

For the participants of this study, multiplicities were emotionally and socially impactful and could not be viewed separately from physical symptoms of illness and worries associated with medical complexity. In addition to feeling stress, participant 16 believed her living situation itself that caused her most recent medical deterioration. She was contending with a landlord who was "a horrible person". She found this frustrating because of the potential implications of her living situation on her physical health. Participant 16 had long-standing diabetes, atrial flutter, and chronic foot wounds. She felt that her bilateral cellulitis could have been avoided were it not for the environmental conditions in which she lived. During her readmission, she was in the process of moving to a new residence and reflected that,



*The landlord didn't want to do nothing to the place. The people's [referring to the upstairs neighbors'] pipe for their bathtub broke, and water rushed in between the walls and everything in the bathroom, flooding the bathroom floor, which is no fun. And then what happened is that, like my brother told this, told this to me when he was home and everything, and I was here in the hospital. And he said that ah, he had to get the landlord to get off his lazy SOB ass. Excuse the language, but anyway, ah. He told him, he says "look, he says, "I'm not paying anymore rent here." And he says, "I'm leaving!" He says "enough's enough!". He says, "you haven't done a damn thing to the place", and he says, "I'm not putting up with anymore of your crap!" He says, he says, "you're a slumlord, you don't give a damn about anybody, and that's it, we're leaving!"*

There was a reciprocal complexity associated with participant 16's living situation. Her health issues meant that she was vulnerable to the condition of her home and the condition of her home compounded her health problems.

Participant 12, like participant 16, was attempting to navigate a major life transition from her hospital bed. Participant 12 is a young wife and mother with long standing MSUD. She caught COVID-19 in the initial weeks of the pandemic while working as a receptionist in a hair salon that ignored proper protective equipment (PPE) and social distancing practices. As she fought to become medically stabilized, participant 12 was frantically attempting to find alternative employment because she could not cope with the fear of returning to her previous employment. The multiple complexities in her life occupied her thoughts as she described acute on chronic illness along with intense fear and anxiety. During her extended hospital stays she was quarantined from her baby along with the rest of her family. She detailed the many anxieties and fears she experienced for herself, her young child, and her parents with whom she also

resided. It was clear in the way that participant 12 spoke that the adversities in her life were accumulating and interconnecting with her physical health. This quote captures participant 12's turmoil amid acute medical deterioration. She described:

*I had really bad anxiety for over a month where I would wake up at, between 12:30 and 1:00 and I would just walk around the house and I would be like "Oh my God I think I've got COVID, I've got COVID, I've got COVID". And my husband and my dad would say "you need to relax" because I would find anything like, chores or anything to do like do my laundry, wash dishes up until, like, 4:00 o'clock in the morning, ...and then I would go to sleep. But I had like the worst anxiety of my life, and I've never had, I've never experienced anxiety before. All this anxiety started when COVID happened and then when, when we eventually went back to work, I was really, really scared.*

Through participant 12's detailed account, it was apparent that multiple physical, emotional, and social burdens were overwhelming at times. Yet, even in the face of being so obviously unwell and exhausted, she continued,

*I think it's kind of crippled me in a way. I'm a lot older and I can handle it and I can tell people, hey I feel this way, I feel that way. But when you have a little boy at home that doesn't know what's going on or how he feels, it just terrifies me to my bare bones to even think that because of me having a job, like I have, can cause him to be really, really sick or can cause my parents to potentially pass away 'cause they're older now so, so this is, this was like my last straw. So now I'm trying. I will go to sleep late just to be able to see what jobs I can find that don't have to do with salon work. Because it's not a safe environment, not even for people that go in there and get their hair dyed and stuff like*

*that. If the salon manager or owner, if they don't stick to their regulations, then they won't care if any of the clients do.*

When describing her current experience with worry, participant 12 seemed burdened not only by her own anxiety, but also about the impact of her absence on her baby.

*He's felt almost like I feel, like he's, he's felt like we've abandoned him especially the first time (her initial admission) Because he couldn't see, not me or his dad. He was stuck just with my, my dad. Now, he loves my parents, but when he doesn't see his parents, it tears him into pieces. And now that I'm back here (in hospital) again, all he does is cry at home. Like I can't even talk to my husband for very long 'cause he'll just start crying. So, I think what he would, he would say is "why you going away mom?", you know? It breaks my heart because I know that if he could say or understand what was going on, he would be very, very sad and cry still but at least he would have some understanding as to why I am here. But I, I know it just tears him to pieces. Cause, like, I do things way different than my husband does, so to him his dad is amazing but with me he, we play, we do a lot of stuff together and it's just - and it's not the same. And so, his, his nights are awful I've heard. He wakes up every so often 'cause he's calling my name, and so [husband's name] has to get up and tell him that I'm, I'm going to come home soon. That I'm just going to get better 'cause I'm sick.... My dad says that he sometimes he just kind of sits there he just kind of stares up like, at the sky or the wall and he's thinking.... So, that kind of stuff just tears my heart because he, he doesn't really need to go through this kind of stuff....*

Participants described how it was challenging, if not impossible, to isolate their multiplicities from their current experiences and symptoms. A picture of heightened complexity

began to emerge from data as I contemplated the details of what I was learning from participants' experiences.

### *Negotiating and Adapting to Changes in Social and Familial Spaces*

When navigating the challenges of life with multimorbidity and/or acute illness, participants in this study were in a continual state of navigating interpersonal relationships. Relationships were significant in how participants coped with disease. Along with ever-changing disease processes and multiplicities, relationships were negotiated and challenged to adapt. The dynamics of relationships with loved ones revealed how alone and lonely the experience of CCD can be.

**Relationships are Impacted.** For participant 5, it became increasingly clear that she felt a weight of additional burden as she reflected on her marriage of 61 years. Throughout the conversation she spoke with a sense of resentment but also guilt as she reflected. While emphasizing "my husband cares for me," she went on to describe how their relationship, while loving, provided minimal emotional or practical support to her, particularly at times when she needed it the most. She attributed her longevity and ability to manage with CCD to her own self-determination in being a self-described "fighter." In reference to the relationship overall, participant 5 commented she assumed "all responsibility for everything." However, further into the conversation, a sense of guilt emerged as she stated, "I'm a burden to him, I don't care what he says, I know I'm a burden." She reflected on years of experiencing her husband make comments about her health struggles, as well as saying things like "you take care of it, don't bother me, I'm not interested." She said, "he's not interested in the fact that I'm sick."

Despite her anger, participant 5 could see the nuances of their relationship. She appreciated her husband's fear but was visibly hurt and frustrated by his words and actions.

Participant 5 remarked, “nobody in this world will ever know how much pain I’ve handled because when I said I want to go to the hospital, he said “no, no, no, you’re strong, you’ll be OK” As she considered the necessity of her admission and the physical and mental toll of it, she added, “I’m better off there (meaning the hospital), they’ll take care of me.” Participant 5 noted in the interview that, in her time of greatest need, her husband’s biggest concern was who would be there to take care of him. She reflected on the good sense it made to her that they transition to supportive living accommodations. Her husband was in the early stages of dementia, but she encountered resistance to this idea from him, despite support and intervention from her physicians and nurses.

Participant 6 also alluded to a sense of guilt as he described the impact of his illness on his marriage. He pointed to the disparity of work and responsibilities his wife assumed because he was unable:

*Oftentimes she's put in the position where she has to alter her plans to suit my plans and that, that, that troubles me a lot.*

As he described dynamics between him and his wife, participant 6 also spoke in a way that suggested she might be trying to establish boundaries in their relationship:

*She says 'you've gotta look after yourself. You tell me what to do and I'll do it,' but, ah she doesn't really. She's not, she hasn't been involved at all in, in medical decisions and she doesn't want to be involved now. She figures that that's outside her purview, sort of thing, so she just accepts the word of others and what they tell her is going on.*

While navigating her relationship with her husband amid his declining health and readmission to hospital, participant 6’s wife was also grieving the loss of her mother. Participant 6 spoke with appreciation of and empathy for his wife’s experience:

*She was doing a humongous amount of work trying to, yeah, get, get me looked after. Her mother had just passed away. She passed away the day after I was admitted to hospital and, and so she had a lot of pressure on her. She's just gone back to work now and that's after a month off that they gave her, and she's still not sinking into it, so what's going on? She gets, she gets crying sometimes and she gets, you know, it, it's hard on her and my daughter's helping out it as much as she can, but there's really not a lot she could do because she doesn't, she doesn't feel as close to grandma as my wife does, her child. So, she's just riding the wave as she can.*

Participant 6's illness was a stressor within his relationship, but he was dependent on that relationship for care and support. The relationship impact for participant 6 and his wife arose in a mismatch between what participant 6 wanted and felt he needed from his wife in terms of care and what she felt able to provide under the circumstances.

Participant 1 also commented on relational complexity. He recalled guilt about his progressive appetite loss because he was unable to eat food his wife had gone to trouble to prepare for him. Participant 1 felt guilty because he could not show a reciprocal to effort to his wife's by eating properly on account of his poor appetite and ongoing nausea. This dynamic added to other underlying concerns about their relationship as he explained, "... my wife is not the type who can handle having a sick person on her hands. She panics." Eating food someone has prepared is an ordinary everyday occurrence, but participant 1's comments show how some of the everyday, ordinary aspects of life can add to complexity.

Participant 7 also noted the dynamic of close relationships as she reflected on her role as primary carer for her mother, who resided in a nursing home and the tensions felt in the face of

not getting from her mother what she needed while also not being able to rely on her own daughter, a mother to twin toddlers during her time of need.

*My mother is 81 or 91 and she's in an old folk's home and they're in 'lock down' and have been since the middle or whatever of March. And she's going crazy, and I'm like "you know what mom?". I was her major caregiver and so, you know, anytime she had any appointments, I was the 'go to' person, then driving her. And you know and that now all of a sudden, I'm on the flip side of this and I'm like "wow did I ever do a lot for you." Like they realize that, and I just got to the point with her where I was like, I had to put her over there and say, 'you stay there, I need, I need to look at this.' You know, she used to be a nurse so she is like 'you should do this' and 'you should do that' and I remarked, 'I don't need help from you, you're my mom. Speak to me like my mom.' Oh, we had a good growing experience.*

Participant 7's medical complexity occurred amid numerous relational dynamics and supports in her life seemed to be limited in the degrees to which they could support her. Even so, participant 7 remained committed to her recovery and was independent and proactive in educating herself about how to manage her illness.

Relationships are fluid and evolve with varying degrees of agreed-upon nuances and dynamics. What the data suggests is that dynamics are not always completely within the control of both individuals. When health declines occurred, participants did not always experience or feel comfortable requesting more from their loved ones owing to existing dynamics and complexities within their relationships.

### ***The Healthcare System is Complex***

Healthcare systems in general are complex. As such, the idea that experience of a complex healthcare system would feature in the data is perhaps not surprising. Although it might seem like a mundane finding, the fact that participants experienced the health system as complex merits discussion because it offers insights that might help with addressing aspects of healthcare delivery that internal medicine patients find problematic. Despite health system complexity, participants in this study spoke about experiences of accessibility and feeling supported by the system, regardless of the point at which they accessed it. Thus, even though the system itself can be complex, system complexity does not preclude a positive and responsive experience for patients.

Data in this study showed how patients experience healthcare as a non-linear, interconnected system in which they play important roles in monitoring their symptoms, sharing responsibility for reciprocal communication with outpatient medical professionals, as well as seeking out support when circumstances became tenuous. Discharge from hospital and the transition back to the community was overwhelmingly experienced as well organized, communicative, and collaborative among healthcare professions and between participants and their loved ones. Most participants described a system that was flexible, accessible, and accommodating at all points of access both from within the community and acute care. Regardless of where along the illness-wellness continuum participants were, medical stability remained fluid, and participants seemed to anticipate accessing the healthcare system, including acute care, at various junctures. Participants described the healthcare system, with all its intricacies, as effective in meeting their needs regardless of the point at which they accessed it.



Participants were all readmitted through the Emergency Room (ER) where they had arrived independently or per ambulance.

**The System is Responsive.** Considering several participants in this study experienced their declining health to have occurred precipitously, it was encouraging to learn that most viewed their encounter with healthcare system as a positive experience. For participant 4, her view of the healthcare system was influenced from a negative to overwhelmingly positive perspective when she reflected:

*Yea, before I got sick, I heard about the [name of hospital]. I was scared. But it's all, it's not true. I heard really scary stories. You know yesterday we didn't wait long at the emergency. We waited less than, my husband told me not even an hour. I'm glad they did what they did and how fast they did it. I have no problem with the emergency, not, both times. So, you know, I want the people to know that the [name of hospital] is not a monster. [Name of another hospital] is great also. When I was transferred here it was midnight. Well, the team here, whatever, was great! And so was this morning.*

Participant 5 expressed repeatedly that she “wanted to go to the hospital.” While acknowledging she waited in the hallway for “quite a while” in the emergency room (ER), she did not view this negatively. Participant 5 stated her husband, while trying to talk her out of going to the hospital, warned her, “you’re gonna have a 10-, 12-hour wait, you know what it’s like,” to which participant 5 replied, “but I’m better off there – they’ll take care of me.”

Participant 7’s readmission to acute care was at the direction of a dermatologist she had seen after a nurse at her liver specialists’ office noticed alarming symptoms of skin breakdown and burning on her feet. Participant 7 found it remarkable that the nurse would make these arrangements considering the purpose of her visit was to discuss ways she could increase her

protein intake into her diet. After being assessed right away by the dermatologist, participant 7 recalled, “he just took one look at me and he said, “I never see these in the office. They’re always straight to emergency because they are so severe.” Participant 7’s daughter drove her from the dermatologist’s office to ER. She recalled how smooth the transition was for her on arrival because of the support of the dermatologist:

*He was fantastic, this dermatologist and he wrote out a letter, point form, to the [admitting hospital name]. My daughter was with me so she drove me over here, but the dermatologist just told the admitting doctors this is what you need to do, in order, and so the ER doctor said “I understand you have a letter for me” and I gave it to him and he just went, “that’s perfect, that’s exactly what I need.” He put it in my chart, and they just followed along and did everything that he had recommended. It was pretty interesting watching all of these different departments try and figure out what was going on.*

In addition to dermatology recommendations, an urgent inpatient ophthalmology consultation was organized for participant 7 at a different hospital. She recalled, “They set me up, took me over to [name of hospital]. Just took me right in, I was already pre-admitted.” After examining participant 7’s eyes, the ophthalmologist was prompt to reassure her the results were positive. The paramedics remained while participant 7 attended this appointment and they brought her back to the hospital where she was admitted. She said, “I had never been in an ambulance in my life, you know? So yeah, things have worked like that. It’s just really been amazing.”

Participant 10 also found the healthcare system was an immediate source of support in moments of uncertainty. After experiencing multiple symptoms of deterioration, including anxiety, participant 10 phoned 811 because she was feeling apprehensive about what she should do. After discussing her symptoms with an 811 operator, participant 10 phoned 911. On her

previous admission, “they just left me laying in the hallway,” but readmission was a very different experience and she received care right away. Participant 10 described:

*I started seeing the doctors one after the other. I don't know if they go by “a, b, c” or whatever, but I started seeing them in alphabetical order. They got it looked after and took care of it. All of the doctors here are fabulous. They're fabulous, they sit and talk like you're talking now.*

Readmission was also experienced with a sense of security and confidence for participant 8.

After a history of complications following his liver transplant, participant 8's first point of access to medical care was at [name of hospital] when it came to his worsening abdominal pain. After a year of close monitoring and frequent readmissions, participant 8 stated [name of hospital] was the only form of medical surveillance he would consider accessing in the weeks after his liver stents were inserted:

*A lot of stuff is unknown to the doctors. Cause I have a whole team of, like there are six doctors that focus on my issue, ah, so it's a, it's an unusual situation because normally you get a liver transplant and once you get the transplant you know, after a few months you get back to normal... So ah, yea and it's just one day at a time, one step at a time. I come into the hospital for a .... For, for, for something and sometimes I'm supposed to be like "in and out" or "in one day and out the next, and so far, it's been at least a week, and in some cases, months before I leave.*

Throughout the study, participants experienced similarities and differences in health deteriorations, but they all shared a similar experience that the healthcare system was accessible and responsive, despite its inherent complexities. Discharge plans prior to readmission were mostly experienced as well organized. Safe transitions back to outpatient care were supported

with effective communication and collaboration with participants prior to leaving the hospital. Participants were directed to follow-up with GPs and specialist appointments as well as pre-arranged nursing support and laboratory and diagnostic imaging follow up. When concerns arose, or symptoms became more urgent, most participants described easy (last minute) access to GPs or confidence in knowing they could return to ER, independently or by ambulance. None of the participants felt their healthcare was neglected or expressed feeling vulnerable to a lack of follow-up as they looked to the future. When urgent care was needed, they found the healthcare system responsive at all points of access.

## **Theme 2: Relationships Matter**

The second theme, *Relationships Matter*, reveals the inclination of internal medicine patients in this study to be self-possessed, self-determined, and integral partners of their healthcare team. Participants saw themselves as essential to the team and its overall processes and were committed to their treatment plans. Participants also described the value of relationships with healthcare providers and the elements that contributed to their effectiveness. Participants described life with chronicity as one where symptoms change, and additional support and guidance from healthcare professionals are often needed. With disease trajectories that are multifaceted and ever-changing, participants expressed the value and security they placed on having long-standing relationships with healthcare providers. When describing disease progression, participants consistently reflected how their team was always accessible and available to them. Their perspectives suggest their network of interdisciplinary team members were also dedicated and supportive in their roles, in turn communicating to patients the value that *relationships matter*. Within this theme are two subthemes, *Patient as Partner* and *Successful Relationships*.

### ***Patient as Partner***

A dominant theme across the data, was descriptions of supportive and collaborative relationships between participants and healthcare providers. Patients expressed they were welcomed and invited to partner in their healthcare. As reflected in all but two interviews, participants of this study described that they were motivated in their care and assumed a proactive role within their healthcare team as self-advocates and as reliable informants about their experiences and preferences for care. Participants described, how within a collaborative dynamic with providers, there was a basis from which to engage in self-determination and the sense that they were co-piloting their own health trajectories.

Collaborative, relational dynamics between healthcare providers and participants was a shared experience across the data. For participant 17, this seemed to support her readiness and ability to be her own advocate. During her experience with medical complexity, she was awaiting a definitive diagnosis while experiencing a range of concerning medical symptoms. Despite it being a time of uncertainty, participant 17 described being actively engaged in seeking answers.

In the days before her readmission, participant 17 finally received a definitive diagnosis of small intestinal bacterial overgrowth (SIBO). Participant 17 described SIBO in detail and explained why this diagnosis "fit" with her symptoms. She researched her condition to proactively incorporate healthy practices into her diet to avoid or minimize future complications. When asked if she felt that she was a partner in her care, participant 17 said,

*Well, I think the patient has to be. - Because they're the ones who should know their own body and what they feel. I was Type 1 Diabetic for - um, 58 years. I pay a lot of attention to what my body's telling me, I have had to over the years.*

Participant 17 used the word “we” as she discussed concern about her sodium. It suggested to me there existed a reciprocal relationship with her physician as opposed to a singular, perhaps passive, or recipient-oriented dynamic. The ways several participants in this study spoke implied they naturally situated themselves in the centre of the team. For example, participant 2 referenced frequent bouts of ketoacidosis as something ... “which *we’ve* [emphasis added] been really working on.” Participant 7 stated it in a similar way, saying “*we’ve* [emphasis added] got to address sores that are inside my mouth cause I’m still not eating. I’m gaining but I’m forcing myself to eat.” Participant 10 recalled, “*we’re* [emphasis added] still trying to figure out what caused that pain,” and participant 11 said, “...so, that’s why they’re going to do an endoscopy tomorrow. Because I did have some tarry stools, and so, *we’re* [emphasis added] going to see this, just have another look at that.”

Where the participants situated themselves within the team, while subtly communicated in the interviews, may reflect a shifting in norms and responsibilities for care, reflecting how they are able to experience being in partnership with the healthcare team in a way previous, hierarchical provider-patient relationships have not allowed.

**Self-Determination/Personal Responsibility.** Within the theme, *Relationships Matter*, the impression of self-determination and personal responsibility was apparent in the language of most study participants. Most participants described their health as well as their experiences within the healthcare system as their personal responsibility. They described a proactive attitude as essential to maintaining the best possible health. Moreover, proactive communication with the interdisciplinary team was often initiated by participants who approached their health from the perspective that regular consultations were essential for self-monitoring symptoms and ensuring

treatment regimens remained optimal as time and disease trajectories progressed. Participant 7 described herself stating,

*I'm not a wallflower, ya know? I tend to take responsibility for my health and its sort of like, you tell me what's going on. And so, I'm very proactive when it comes to speaking with the nurses and the doctors and, you know? Explain to me, 'OK, now it's turning into this', what does that mean? - It's not like I'm sitting here going [gestures a passive gesture].*

Participant 7 expected to play an integral part in her treatment and recovery. It was important to her to understand how to manage her health needs and viewed her own engagement with recovery as central to her treatment. For several other participants, self-determination was reflected in the assertiveness with which they held to their personal judgments about their level of comfort with plans for follow-up and monitoring. For participant 11, this was evident in her recollection of being assessed in the ER:

*The first time I was in though, the ER doctor, he said, "Well, yes there is liquid on your chest, on your lung. So, it's up to you whether you go home or stay in the hospital". And I'm like, I'm not going home, no*

Participant 5 spoke with similar conviction when she stated, "as long as I'm infected, I'm not leaving here," and for participant 7, "I'm not going home with feet like this." Within these situations participants seemed to have the confidence to project where their own limitations were when it came to self-care and critical thinking around disease management and progression. Other participants expressed a similar self-determination by clearly delineating where they would be assessed and monitored. For example, participant's 5, 8, and 15 expressed self-

determination in their insistence that [hospital name] was the only healthcare setting they would consider seeking acute care as this was where their liver transplant team members were based.

When describing the dynamics associated with monitoring their health, most participants described their roles within the team as integral to their optimal and effective functioning. Participant 15 described his role as reporting his symptoms relative to the treatment plan and for receiving ongoing feedback for his continued health maintenance and understanding. Participants described being central to their ongoing health trajectory voicing need for continual collaboration with the interdisciplinary team.

Most participants needed to understand the details of their disease management, and when lacking necessary information, they proactively sought it out. They cited regularly initiating communication for inpatient and outpatient health concerns, and referenced initiating phone calls with their GPs, transplant teams, metabolic team, or pharmacies. Participant 16 explained, “well, I make sure that I communicate with her [family GP] a lot...I phone her about every two weeks”. Participant 8 stated, “And I ask questions.... you know.... And if I don't get it from one, I ask another one, you know?” This was like participant 7, who recalled questioning a pharmacist regarding her medications:

*The box said one thing, but the instruction said something different, and I just was unclear, so I asked him, and she said, “Oh yeah when you finish this [antibiotics] then you finish those [flavonoids]”.*

Participant 7 expressed some frustration with one outpatient pharmacy experience. She felt perplexed by their lack of communication with her around the implications of taking large doses of steroids:



*Again, their attitude is sort of like “well, you know, your doctor prescribed this for you, like why are you asking me these questions?” And I’m like “I can ask you as many questions I want before I’m starting to ingest all this stuff”. That really sent me for a loop, I was like that, that’s information I want to have. And you know I need to know that I need to measure that steroid to the centimetre, you know, or the millilitre.*

Being proactive as a component of self-responsibility was present throughout all but two interviews. participant 8 described, “I carry a binder around with me. I keep track of all the doctors’ appointments, all the meds.” Participant 15 echoed a similar sentiment stating, “I took it [copies of health records] to him [a physician] thinking, oh, well you may not have that. - So, I - photocopy everything that I came outta the hospital.”

Participant 7 viewed her own capacity to be proactive as a necessary aspect of a successful healthcare system, stating, “you have to be your own advocate.” Later in the conversation when asked what constitutes a good nurse, she again shifted to self-responsibility:

*Well, I think a lot of it’s to do with the patient, you know? Like, as long as you’re open to them and I’m very like, “Is there anything I can help you with”? Like, I have to apply this cream on several times a day. Well, I don’t need you to come in and put cream on my legs. I can do that, do you know? That kind of thing. Anything that I can do to help them with.*

For most participants, knowledge of their disease processes or treatments was a source of confidence. Participant 17 commented, “Well, I’ve been type one diabetic for 58 years, so I probably know more than they do in those regards.” When asked whether she thought the interdisciplinary team placed a high value on educating, participant 16 replied, “I’ve had diabetic education through...through the different years... So, I know all about the diabetes...”

Participant 1 was particularly forthright about the role of personal responsibility in his health deterioration. He felt a lack of personal ownership throughout his most recent health decline. He stated,

*I was manipulative, probably. I did everything I could to make people think that, you know, you can go home. Looking back, I wasn't thinking well, not that I'm confused. My minds been good all the time. But I guess that's what it was. It was me, not the hospital, not the doctor, and ah, anyway, so I ah, changed my attitude. Now I am in it for the long-haul, whatever it takes. And, and ah, I'm gonna do it right... Anyway, I've reformed... I should have stayed here the first time.*

A sense of personal responsibility seemed to develop for participant 6 as he reflected on his communication with the interdisciplinary team. Participant 6 viewed his readmission as avoidable; he reflected that a more vocal or active stance could influence his level of comfort as he considered his upcoming discharge home from hospital. He said,

*I've voiced a few concerns. They're, they're keeping me in for a few extra days to check on these things, so, so yeah, this is different than last time where I didn't say anything and just basically got sent home.*

The perspective that recipients of healthcare are partners, co-navigating their disease trajectories allows space for patients to take on manageable responsibility and experience some autonomy in their treatment and care. Participant's responses in this theme contrasted with relational structures wherein recipients of healthcare are expected to exhibit a passive tendency and to defer to expert knowledge.

## ***Provider Relationships***

The data of this study reveals supportive and effective relationships between participants and the healthcare team where follow-up was carried out consistently despite the dynamics and complexities of the healthcare system. There appeared to be fluidity and ease with which participants engaged with their inpatient and outpatient healthcare team resources, all agreeing that adequate support was readily available, whether it be within the context of acute care hospital stays or at home in the community. Participants described a dynamic safety net of expertise despite dependence on—and guidance from—a range of healthcare professionals including GPs, homecare nurses, pharmacists, specialists, the liver transplant team, a foot specialist clinic, the guidance of the 811 service, and the collaboration of the metabolic team. While resources were diverse amongst participants, what remained consistent according to most, was supportive and effective medical assistance. Participants seemed comfortable communicating and collaborating with all members of their healthcare team. Many participants described having years of history with providers, which lead to a feeling of connection. In the interviews, participant 5's account of requesting her ER physician contact her regular hepatologist showed connection with and confidence in him:

*I said, "call Dr. [name], he'll tell you what to do with me". I said "he was the one who sent me for my transplant. He knows me for 15 - 20 years. So, call him". In fact, he came down here to visit me today...*

Along with other participants, Participant 5 conveyed confidence in her physician. Participants in this study felt supported not only by the system, but within the relationships they had with all

members of the interdisciplinary team. Many participants had long standing histories with various interdisciplinary team members. Participant 16 recalled,

*...I've been with her for about oh, it must be about, it must be about 20, 25 years now. I mean it's a long time. And like I mean, we get along great, you know. Like, we're, we're like sisters pretty well, you know, 'cause she likes to joke around, I like to joke around.*

Within longstanding relationships, rapports were well established, and this strengthened relationships. Participant 15's wife stated:

*To me they were personal, very personal. Because, in that case we, I had known both of them [referring to participant 15's internal medicine physicians] a long time now. They both worked on me in different capacities, right? I had a connection with them anyway, almost like a friendship I would call them friends because of the way they dealt with me before and everything else.*

Provider relationships were integral to how participants of this study experienced the healthcare system. The ease with which participants felt they could provide and receive communication seemed to support self-management within ever changing and evolving disease processes. There seemed to be a reciprocity between *positive engagement with healthcare providers* supporting *effective interactions with healthcare providers*, which in turn fostered *positive engagement with healthcare providers*.

**Effective Interaction with Healthcare Providers.** While all inpatient or outpatient experiences were unique—and transitions varied based on circumstances—participants in this study described effectiveness of individual professionals as well as the effectiveness of the healthcare “system.”

When referring to effectiveness, most participants felt effective interactions with healthcare providers encompassed such things as feeling equipped with the necessary knowledge and education needed for a successful discharge. Participant 15's wife stated<sup>3</sup>:

*And the [healthcare team] would explain .... explained a bit and, you know, ask, we asked a couple of questions, and the answers were there. Like, they didn't make you feel, um that you couldn't ask a question. They were there to help you and to understand what was going on from your perspective. And they'd share what they were seeing and what they thought. And very humanistic, humanistic way, like you. Gentle's the wrong word, but you knew you could bounce anything back to them and they wouldn't hesitate to give you the answer with no resistance at all. "Is there anything else you need/ want to add or thoughts you're having?" Or like, it was very good.*

For participant 15 and his wife, it seemed the exchange of knowledge and information was conveyed within the dynamic of supportive relationships. This seemed to resonate with many participants. Participant 16 also felt the relational dynamics of the interdisciplinary team contributed to a climate that supported the exchange of information between healthcare providers and herself. When concerns arose, participant 16 recalled phoning her homecare nurse, GP, or foot specialist and received prompt and helpful responses when she felt uncertain or unsure of how to manage or navigate uncertainty.

For participant 8, equipping himself with knowledge and education involved keeping a personal record of his health. He stated,

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<sup>3</sup> Participant 15's wife was invited to participate in the interview by her husband (after they were first approached by participant 15's primary nurse). Therefore, participant 15's wife added her name and signature to the consent form at the same time as her husband.

*Yeah, I carry a binder around with me. I keep track of all the doctors' appointments, all the meds. I have a four-page med list, all the procedures I've done, everything just because my memory doesn't always serve me well. And if I could dig out a report or a med list or whatever that's all written up, it's a lot easier to explain to the doctors especially with you gotta do it several times over. And yeah, it keeps me focused on ahhh, you know what's been done and, and kind of what the next step is.*

Having the necessary knowledge to self-manage was an ongoing process for participant 8 and for most participants of this study. Common across the data was the perspective that effective communication on a regular basis was key to supporting the exchange of information and clarifying new and shifting priorities for healthcare management in practical terms.

When referring to the effectiveness of their interaction with healthcare providers, feeling equipped with the necessary knowledge and education needed for successful transitions was widely felt. Additionally, feeling confident that there was an appropriate plan for follow-up was identified as an essential aspect of this (noted by participants 2, 7, 11, 14, 15, 16, 17), and that when concerns did arise, that the urgency of the situation was met with appropriate timely response (noted by participants 4, 5, 7, 11, 15, 16, 17). Many participants also pointed to efficacious interdisciplinary collaboration (participants 2, 4, 7, 11, 15, 16, 17) as a measurement of effectiveness while the feeling of not being pressured or rushed to discharge (participants 10, 11, 15), and the sense of being well known (participants 8, 10, 15) to healthcare providers were also discussed as important and significant.

**Positive Engagement with Healthcare Providers.** Most participants described supportive relationships with their inpatient and outpatient healthcare providers. Participant 2's descriptions of the interdisciplinary team implied a progressive experience where within the

chronicity of disease, she had experienced gains over time and came away with the perspective that these were arrived at because of positive interactions:

*The teams work really well together, and they really work well with individuals as well. As far as with me, they work, they work really well with me over the years. It'll be about 5 years in April since I've been coming back. I had a coma 5 years ago in April, and I've been here a lot since then and they always make sure that, and they also include my husband and incorporate my support system and stuff like that too. And they question like "is this ....do you think this is ok or are you alright with this".*

Participant 2 valued the quality of her interactions with the interdisciplinary team. Furthermore, she appreciated that her husband was included in her care because her seizures and episodes of hypoglycemia were often outside of her capacity to manage independently.

Participant 15's feedback regarding engagement with healthcare providers agreed with participant 2's. He stated, "I truly believe that they are a team in the true sense of the word."

Participant 4 described positive engagement with the healthcare system in the context of a snapshot in time where she recalled her experience encompassing everyone from professionals in the ER through readmission to the internal medicine unit:

*I never, never once felt like I once had any problem with anybody. That is very important, very important. And I told my husband, "I cannot say that one of them was worse than- No, everyone was fantastic". The nurses as much as their helper. And the doctors, the doctors were, yea, so I will, I will, even if you question me 500 times on the same question, I will not criticize them, donations will come to this hospital instead of being spread out because, yeah.*

When asked about his perspective on healthcare provider interactions, participant 8 explained, “Well, it, it depends on the doctors. Some are very good, and I have an excellent rapport with them. I mean I’ve seen them so often we know each other on a first name basis.”

In specific reference to internal medicine nurses, participant 8 offered insights into a more subtle aspect of his healthcare interactions, saying,

*Well, they listen more, to what the patient says and, they verify that with the doctor and all that sort of stuff. And so now I just find the information I get it from them is very consistent with what the doctor said. And, and ah, also they've had some first-hand experience with other patients that have had the same issues that they know how to comfort more, you know? So, they know they kind of know what you're feeling, like what you know what your emotions are going through as well as well as what pain and, .and what they could to relieve it and that sort of thing.*

Participant 17 had similar feedback regarding internal medicine nurses saying, “the nurses were wonderful...They obviously care about you and listen to you. And, umm, do their best to respond in a reasonable amount of time.”

Interactions with healthcare providers can be influential experiences, especially in the context of felt vulnerability and the implications of some diagnoses. Participant 10 alluded to this when she said,

*I met a fabulous doctor, Dr. [name], and that man stayed with me right up until I had got the answers I needed at that time. Umm, ‘cause he didn’t know what it was. And ah, and it was the cancer coming back.*

Participant 12 spoke with appreciation as she recalled her physician’s vigilance in monitoring her family:



*I know that he was in touch with my entire family when we had COVID. He was just, he called every single day to make sure that they haven't had your symptoms or if they were unwell. He was the one who actually told my dad that he needed to go in for a second check.*

The experiences of study participants reflect interactions where healthcare providers displayed an investment in the quality of care provided and in the relationships with participants. When describing the dynamics of relationships with physicians, participant 15's wife spoke to familiarity of knowing and being known by her husband's interdisciplinary team when she said,

*To me they were personal, very personal. Because, in that case we, I had known both of them a long time now. They both worked on me in different capacities, right? Over the years, so, so they're personal, that's the one.*

Like participant 15, participant 16 also described confidence in her physician that she had developed over the years. She stated,

*I've been with her for about oh, it must be about...it must be about 20, 25 years now - I mean it's a long time. And like I mean; we get along great you know. Like, we're, we're like sisters pretty well, you know. Cause she likes to joke around, I like to joke around; and but I mean we're dead serious about this disease so yeah you know... Cause, I mean that's the kind of bond that her and I have.*

When discussing her experience with the healthcare team more broadly, participant 16 stated,

*Well, the way they care about people and everything. You know like if somebody comes in, let's say like - like for myself and everything, that really need the help, they're right there when you need them right away, you know?*

In reference to the nurses who were involved in her inpatient care participant 16 expressed the qualities she most appreciated were,

*The caring about them. You know, I mean, when they really deeply care about you as a person and everything, that's what I look at.*

### **Theme 3: Specialized Care is Needed**

Participants' experiences suggest acute care internal medicine treatment became unavoidable, not because of unsuccessful discharges, but because disease, continued to progress and became more complex requiring specialized inpatient treatment. Management of medical deteriorations necessitated acute care monitoring and intervention where additional expertise and/or the support of medical technology was readily available. Despite ongoing efforts to monitor and treat patients on an outpatient basis, participants experienced medical deteriorations that required specialized inpatient care. Participants described care involving multiple medical specialists, and access to laboratory and diagnostic imaging that occurred on a more urgent or frequent basis. Nursing surveillance was ongoing, and physicians monitored and checked in with participants regularly. Medications were often administered intravenously, and overall responses to treatment and tracking of disease progression was monitored on a continual basis. Participants did not consider readmission to internal medicine was due to unsuccessful discharges; rather that they remained in a system of care, whether in the community or for intermittent periods within the acute care setting. Within this theme I explore two subthemes: *A Circuitous Route* and *Readmission was Unavoidable*.

#### ***A Circuitous Route***

Within the data, there seemed to be a comfortable fluidity to plans for follow-up in relation to GP and specialist appointments as well as laboratory and diagnostic imaging follow

up. When concerns arose, or symptoms became more urgent, most participants described easy (last minute) access to GPs.

On closer examination, participants seemed to experience life with acute, or acute on chronic illness as one in which they never really left the healthcare system. Professional relationships seemed to carry on with ease as participants transitioned from outpatient to inpatient care, and then return to outpatient relationships. Participants described accessible, responsive healthcare within the community or acute care setting. The decision on whether to return to hospital happened in collaboration with GPs or homecare nurses, but it was more common that participants used their own judgement that the degree of acuity they were experiencing necessitated urgent acute care support.

**A Supervised Tipping Point.** Participants in this study lived with a range of illnesses. Within their experiences were commonalities that suggested disease processes were progressive and became more complex despite close medical surveillance and follow-up. Life as an outpatient was supported through a variety of medical professionals with whom participants remained in regular contact either through in-person appointments, phone calls or Zoom meetings. Most participants stated they had health deteriorations while in regular communication and collaboration with their GPs, specialists, and despite homecare support. Regular appointments and consultations were a usual part of outpatient life, including during the times where they experienced medical deteriorations.

For participant 2, readmission to the hospital was the cause of her missing outpatient appointments with her GP and other medical specialists:

*So, I do go to my family physician, usually once a month. I've had a lot of specialist appointments that I haven't made because I end up sick and in hospital. So, uh, yea basically the follow-ups are there, it's just making it to them.*

Participant 5 recalled medical appointments with her GP once to twice per week for months prior to her original admission and during the time before readmission to acute care. In addition to regular outpatient GP visits and homecare surveillance, participant 5 followed up with her liver specialists regularly and had gone to the hospital for a paracentesis during the time in between discharge and readmission. She detailed her compliance and follow-through on her medical treatments and specified how she also continued to monitor her symptoms and took medications as prescribed.

In the hours prior to her readmission, participant 16 recalled phoning her foot specialist's office after experiencing worsening symptoms of redness, new blisters, and increased weeping edema. The clinic arranged for her to be seen by the foot specialist "right away" but after discussing her worsening symptoms with her homecare nurse—a registered nurse performing scheduled dressing changes for her lower limb cellulitis—she cancelled the foot specialist appointment and sought more urgent care from the hospital.

While participant 17 was discharged from the internal medicine setting without a definitive diagnosis to explain why her sodium levels were continually dropping, laboratory and diagnostic imaging investigations continued with her outpatient gastroenterologist (GI). Additionally, she recalled following up with her internist at his office twice prior to her readmission. However, participant 17 continued to progressively feel unwell. After having her weekly, pre-arranged lab work drawn, she reached a tipping point and determined she required urgent assessment at ER. She was en route to the hospital when she received a phone call from

her internist who directed her to return to acute care due to her lab values; she replied, “I’m already in the car on my way there.”

Medical deterioration within the context of medical supervision was also experienced by participant 15. He and his wife described regular phone calls with the outpatient liver transplant team who monitored his overall symptoms and follow-up on pre-arranged lab work including tacrolimus levels. They also engaged in regular appointments with their GP to monitor participant 15’s overall condition relative to his follow-up lab trends. In reference to his readmission, participant 15 described increasing fatigue and shortness of breath as a contributing factor to a fall he suffered in the days prior to returning to hospital. Participant 15 and his wife recalled the immediate support of the transplant team and the immediate support of their GP through phone call conversations and an in-person assessment from his GP. They described the decision-making process of proceeding with treatment plans based on their GP’s assessment and getting timely access to an appointment for a chest x-ray and serum lab work. However, as the weekend progressed, they needed to renegotiate the plan due to participant 15’s fatigue, weakness, and shortness of breath progressively increased. They recalled they were never felt unsupported by participant 15’s medical team. Whether through the liver transplant team or GP, they found their concerns to be addressed promptly and thoroughly.

Both participant 15 and his wife described a sense of knowing over the course of the weekend, that the situation with participant 15’s symptoms were such that phoning for an ambulance was the best decision. On arrival to the hospital, the experience remained positive as they recalled hepatologist, cardiologist, pulmonologist consults all completed while admitted under internal medicine. During his readmission, the outpatient transplant team remained in communication with participant 15’s wife regarding his condition and plans for discharge home

again. Throughout his readmission, participant 15 and his wife detailed the daily assessments, and regular updates from the interdisciplinary team, who not only kept them apprised of updates and plans, but also seemed to be in close collaboration with one another.

**Multiples in Acute Care.** A theme that emerged in the data from all participants is that hospital stays were supported by medical expertise from various healthcare professionals who carried out their treatment plans with the support of multiples in acute care. Multiples included various combinations of diagnostic imaging testing, specialist consultations, the use of intravenously administered medications, and various other interventions and monitoring that was implemented based on medical instability. While these aspects of care alone are not reflective of advanced medical complexity, as multiples, they reflect a level of medical supervision, intervention, monitoring, and evaluation that was needed in a timely manner and in the context of medical deterioration.

Participant 1's acuity was noted by a nurse who asked him how he would have managed at home. Her words resonated with him; after admission to acute care, he was administered "a couple of transfusions" and specialized tests, and the expertise of several medical professionals were needed to determine the origin and pathology of his intra-abdominal bleeding. Even after readmission and becoming more stabilized, participant 1 recalled,

*So, they were letting me use the staff washroom, so I went in there and, on the one trip and I just projectile vomited. I was in the room, and I couldn't even get to the toilet. I couldn't do a thing. So ah, anyway, I guess, like when the nurse says, "it's good that didn't happen at home" and, and she's so right. And I think they inconclusively still don't know where I am bleeding.*

Participant 1 became increasingly aware of the gravity of his health complications after his readmission back to acute care. In the days after being readmitted, his medical stability was tenuous, and urgent interventions were necessary. As he contemplated the number of specialized tests, consultations, pharmacological, and transfusion medicine interventions, he came to understand that specialized inpatient care was needed. This contrasted with his initial coping where he described manipulating his physicians into thinking his condition was improving so that he would be discharged home.

Participant 2 described multiples in acute care following a precipitous medical deterioration necessitated IV fluids and IV insulin. She noted that even with close monitoring on the inpatient internal medicine unit, and after becoming medically stable, she continued to experience sudden, unanticipated medical instability that delayed her plans for discharge.

Multiples in acute care for participant 7 consisted of diagnostic imaging tests, numerous urgent specialist consultations, and increased support from the wound care team to treat her (worsening) burns. She stated she had bleeding ulcers and was receiving IV fluids and several IV medications. Referring to her peripherally inserted central line (PICC) she stated she had blood drawn “10 times a day easy.”

### ***Readmission is Unavoidable***

Most patients in this study described a life of continuous monitoring and follow-up where disease processes changed and were not always predictable. Despite the perspective of being knowledgeable about self-care and monitoring, participants experienced precipitous changes in medical stability in the context of lives where regular and short notice access to medical support was available. Out of 17 participants, 15 thought that their readmission within 30 days of discharge home was unavoidable. Most participants described access to, and relationships within

the healthcare system that suggested they never really “left” the system. Outpatient laboratory and diagnostic imaging studies were tracked, and homecare support was considered helpful and effective. When symptoms warranted and/or lab results indicated, participants self-identified or were guided back to an inpatient system that was perceived as supportive and efficient. Of the two participants who felt their admission was potentially avoidable, only one (participant 14) felt that something in her care had been overlooked.

**Always in the System.** Out of a total of 17 participants, participants 4, 5, 8, and 15 had previous transplants where they had regular outpatient meetings with their respective transplant teams, and one (participant 12) conferred with her outpatient metabolic team regularly. Most participants described strong relationships with their GP's and various other resources including homecare nurses, pharmacists, and outpatient medical specialists. Participants overwhelmingly self-identified they had a wealth of support and felt equipped with the necessary knowledge and information to support safe transitions and optimal health. Transitions were supported by strong communication and collaboration among healthcare professionals including participants and their loved ones. Participants describe a system that was responsive, where healthcare providers within the system—both in the community and within the acute care setting—were highly effective in their roles and established strong relationships with participants. Even amid the complexities of CCD, patients overwhelmingly described a life of autonomy and collaboration in relation to their health care. Although participants' diseases changed over time, what seemed to remain constant was the sense that they were not alone. Participants felt that when support was needed, it was readily accessible and that they received high quality and supportive healthcare.



## Chapter Summary

The thematic analysis presented in this chapter comprised three themes: *Life with Medical Complexity is Complicated*, *Relationships Matter*, and *Specialized Care is Needed*. The themes answer the question, *what are internal medicine patients' experiences of readmission?* The themes describe study participants' journey through medical, social, and relational complexities associated with CCD.

Complexity was deeply imbedded in the experiences of participants. Complexity was shown to have more dimensions than simply physical or physiological complications associated with illness. Negative consequences of disease process(es) interrelated with psychosocial and relational complexities, which, cumulatively, have an impact on how complexity was experienced. This kind of complexity is fluid and unstable. For the participants in this study, they experienced the healthcare system and relationships within it as a stabilizing force. Participants were able to partner with healthcare providers to navigate their way through medical complexity. Where readmission was required, participants saw this as unavoidable and a consequence of their complex circumstances rather than as a failure on their part or the part of the healthcare system.

In the following chapter, I take the insights derived from the thematic analysis and discuss them in relation to practice and the existing literature. I explore how the thematic analysis offers opportunities for nurses to think about patients' experiences in ways that also open possibilities for helpful, responsive, and affirming nursing care.

## Chapter 5: Discussion

In this study, I sought to learn how internal medicine patients experienced readmission to acute care within 30 days of discharge. Thematic analysis of data indicate there are numerous aspects to this experience and that these aspects serve to create and sustain complexities in experience of illness and its treatment. These complexities are elucidated in the three themes: *Life with Medical Complexity is Complicated*, *Relationships Matter*, and *Specialized Care is Needed*.

In this chapter, I present a discussion based on the analysis that was offered in Chapter 4. The discussion draws upon the findings from the study and the current literature to explore how the themes, *Life with Medical Complexity is Complicated*, *Relationships Matter*, and *Specialized Care is Needed* inform and address the existing gap in literature related to the experiences of internal medicine patients. For clarity and flow, this chapter is structured according to the three themes that were identified in Chapter Four. This thesis is written for the requirements of a Master of Nursing degree and, as such, I make links to registered nurse practice in this chapter as well as in the recommendations in Chapter Six.

### **Life with Medical Complexity is Complicated**

Participants in this study experienced disease as multifaceted, progressive, and unpredictable. Participants described extended periods of uncertainty and change often within the context of multiple chronic conditions. Although participants got to know their treatment regimens, they were also in a constant state of revision, depending on laboratory and diagnostic imaging trends, pharmacological implications, and the input of various interdisciplinary team members. Change was, thus, an intrinsic part of participants' lives, and symptoms required diligent surveillance by both participants and healthcare professionals.

Participants in this study described experiencing medical deteriorations precipitously. Despite urgent access to professionals who provided regular surveillance, medical deteriorations were such that readmission became necessary and unavoidable from participants' perspectives. Study participants did not consider readmission to be the result of failure on the part of healthcare professionals or the health system, but rather as an inevitability occurrence given their medical complexity.

Although there was much in this study that was surprising to me, the ways in which participants in this study experienced medical deteriorations resonates with my experience as a registered nurse who practices in acute care, internal medicine. Much of what informs nurses' critical thinking when caring for this patient population is the awareness and anticipation that treating one issue will have broader implications that will need to be further tracked and monitored (Fraser & Taal, 2016). My experience and the perspective of some participants in this study suggest that patients with CCD can rapidly deteriorate even without an initially detectable or apparent cause. Awareness of instability, fluidity, and multiple complexities from the basis of registered nurses' knowledge of patients' presentations and how nursing care is composed in response.

Despite awareness of instability, fluidity, and complexity, nursing practice in internal medicine still follows a linear trajectory from admission to discharge. Registered nurses compose care to prepare patients to return home or to longer-term care. As patients become medically stabilized, nursing interventions focus on equipping patients to sustain recovery and notice and report changes in medical stability. One of the ways that this is accomplished within the scope of registered nursing practice is through patient education, provided at different stages of a patients' admission (Yeh et al., 2018). The findings of this study suggest, however, that medical

deteriorations for patients with CCD are not entirely foreseeable or within the capacity of healthcare providers to predict with absolute certainty. This means that simply educating patients to undertake effective self-care and self-monitoring is not enough to prevent or arrest deteriorations. Multidisciplinary healthcare teams, of which registered nurses are a part, increasingly rely on standardized discharge lists and patient-centred care planning protocols to ensure care is individualized and complete (Drake et al., 2017; Soon et al., 2013), yet these practices and safeguards also cannot prevent unforeseen challenges and precipitous changes in patients' conditions.

The readmission experiences of participants in this study lend some support to existing literature that highlights complexity in CCD. In a recent study, Wiley et al. (2018) investigated whether increasing morbidity would independently predict an increase in 30-day readmission despite a nurse-led, multidisciplinary follow-up protocol for all study participants. The study results revealed readmissions were more strongly associated with complexities related to increasing morbidity (greater complexity correlated with higher readmission rates) rather than the quality of discharge practices that were controlled with a standardized, high quality multidisciplinary protocol. These findings might suggest that something other than standard discharge practices is needed for patients in this circumstance.

Increasing medical complexity was cited as a dominant factor in additional literature examining readmission. Through an international retrospective cohort analysis of 21 acute care hospitals, Brunner-La Rocca et al. (2020) investigated 30-day readmission in patients with multiple chronic diseases. Results showed that one-third of participants were readmitted with the same condition as their initial hospitalization, while over half were readmitted with conditions other than their previous index diagnosis. Of the participants whose readmissions were due to

reasons other than previous admissions, 10 – 35% were due to instability of other comorbidities. Out of a total of (n = 822 929) readmissions, the median time until readmission was 11 days regardless of whether participants were readmitted with the same or a different disease process from their initial admission. Researchers concluded that readmission in multimorbidity is common and should be investigated in the context of concurrent disease processes as well as index diagnoses. Australian researchers Westley-Wise et al. (2020) arrived at a similar conclusion. Through a cohort study of 38 156 participants, 21% (n= 8013) were readmitted within 6 months of discharge, with 8.2 for every 100 index admissions within 30-days, and 12.8 for every 100 index admissions between 1 and 6 months. Most participants (61.2%), in both readmission demographics (n= 23 351), were readmitted for reasons other than their index admission. For patients, living in the context of constant, ongoing instability or unpredictability is demanding and, over time, coping resources can be diminished (Duguay et al., 2014). Therefore, nursing care might be enhanced by incorporating approaches that assist patients to understand and manage through experiences of instability and unpredictability. Westley-Wise et al. (2020) also recommended that healthcare systems need to transition away from single disease approaches, where care is often fragmented amongst a range of healthcare providers, towards a system that is less disjointed.

CCD poses considerable adaptation-related challenges for healthcare systems. When healthcare systems are organized around treatment of individual diseases, fragmentation of care has been shown to occur (Damarell et al., 2020; Hajat & Stein, 2018; Palladino et al., 2016; Ploeg et al., 2017; Roberts et al., 2015; Wallace et al., 2015). While in the acute care internal medicine setting, internists oversee the care of patients with multiple disease processes while internal medicine nurses provide 24-hour a day surveillance and care. There is immediate access

to a wealth of healthcare resources as nurses continually monitor subtle and overt changes in patient symptoms. However, this level of surveillance is not available in the community. While study participants had urgent or short notice access to medical support in the community, the care was more fragmented compared to the acute care internal medicine setting.

Fragmentation of care is a concern in numerous care contexts. As well as the fragmentation that happens through care being given by multiple community providers, fragmentation happens in internal medicine (Damarell et al., 2020; Hajat & Stein, 2018; Palladino et al., 2016; Ploeg et al., 2017; Roberts et al., 2015; Wallace et al., 2015), psychiatry (Conlon et al., 2020; Hagen et al., 2017; Lavin et al., 2017), and outpatient community settings. In each of these contexts, examining how nurses practice is one opportunity to reduce fragmentation. Internal medicine nurses' knowledge and expertise could be used to facilitate greater continuity, and stronger processes to bridge the gaps that can form when multiple specialists are simultaneously treating one patient but in isolation of one another, particularly in areas of practice where higher level of fragmentation tend to occur. Nurses do not practice in isolation from healthcare systems, however, and any review of nursing practice necessitates a review of the broader health system to explore and develop practices that are realistic and sustainable within broader systems of care delivery.

The findings of this study suggest that complexity is not a metaphor for multimorbidity or internal medicine. Rather, complexity is an ontological phenomenon; participants' whole life as it was lived and experienced was complicated. In this context, complexity is the sum of its constituent parts and extends to a great many aspects of life. While multimorbidity was a significant contributor to participants' experiences of complexity, it represented only one aspect of what contributed to the theme, *Life with Medical Complexity is Complicated* in this study.

Another aspect of complexity for participants occurred in relationships. Relationships with significant others were deeply affected, at times causing varying degrees of emotional burden to both partners. Family and social relationships are one way that patients can gain support, however, for that support to be realized and optimized, attention needs to be paid to how to sustain and strengthen relationships (Wong et al., 2022). When preparing patients for transition from acute care, assumptions that familial or close relationships will be supportive might be made in error. In the case of participant 5, the dynamics of her marriage eroded her coping and resilience.

Being able to cope seems like a basic yet important need for participants in this study. Stress, as characterized in the subtheme *Multiplicities*, can permeate to all areas of life. Although major life stressors occur for many people in different contexts, what made them so significant in the lives of participants was that stressors could not be placed to the side amidst acute medical deteriorations. Instead, stressors coalesced with and further complicated experiences of acuity. The emerging portrait of complexity reminds us that medical complexity can have a cumulative impact where disease and social contexts interrelate (North et al., 2016). This highlights the importance of providing holistic, person-centered care in a way that acknowledges how mental, emotional, and spiritual strife coexist with, and contribute to physical health. Consequently, *patient-centered* as opposed to *disease-centered* care paradigms need to remain the focus for healthcare delivery in internal medicine.

The theme *Life with Medical Complexity is Complicated* conveyed the lived experiences of internal medicine patients as they navigated readmissions. Study participants perceived readmissions as unavoidable and to have occurred because of medical complexities unrelated to the quality of care they received. A review of literature suggests readmissions among people

with multimorbidity are more likely to be associated with medical complexity rather than the quality of discharge processes. The implications from the literature and from data in study suggests that even in the context of intervention, readmissions occur. The findings of this study also illustrate how complexity is embedded in life and not easily resolved for patients with CCD. In the absence of being able to intervene in readmission rates, and in the absence of being able to resolve the complexities of life with CCD, nurses need to examine aspects of patients' experiences that are amenable to nursing intervention and find ways to strengthen resilience and resources for managing complex circumstances.

### **Relationships Matter**

The second theme of the data analysis is that *Relationships Matter*. Within this theme were two subthemes, *Provider Relationships* and *Patient as Partner*. Participants repeatedly expressed their relationships with healthcare professionals were a source of strength amid the uncertainty and enormity of medical complexity. There was a deeply felt appreciation for healthcare providers and participants perceived them to be committed to relationships with patients and providing high quality care. Participants situated themselves within the healthcare team and were self-determined in their roles as co-navigators through their health trajectories.

Within the context of these patient/provider relationships, the balance of power was illustrated in patients' descriptions of their personal responsibility to participate in care and support synergistic relationships with healthcare providers. Amid acute health deteriorations and ongoing medical complexities, participants drew heavily on provider relationships, while situating themselves as partners amongst the interdisciplinary team. Effective relationships between providers and patients may have positively influenced the role of patient as a partner, or perhaps it was the patient acting as partner that enabled development of effective relationships



with healthcare providers. Even though a cause-and-effect relationship was not tested in this research, it was clear that the cultivation of a relationship was valued and considered helpful by participants.

The data analysis of the theme *Relationships Matter* conveys two elements of what forms the basis of quality healthcare, provider relationships and patients who align themselves as partners in their care. With such positive data, it might seem logical to conclude that there is little to be learned from this theme. However, a review of literature suggests the experiences of participants of this study, while encouraging, might be tenuous in the context of epidemiological shifts in CCD. The literature reviewed in *Life with Medical Complexity is Complex* revealed readmission is positively associated with increased morbidity. This prompts thoughtful consideration of the challenges and implications of increasing morbidity for people with medical complexity. Given that increasing morbidity places people at a higher likelihood of readmission, perhaps this also makes this patient demographic more vulnerable to reduced coping practices related to their self-perceived quality of life.

In a systematic meta-analysis of peer reviewed original studies investigating multimorbidity with validated quality of life assessment tools, Makovski et al. (2019) found that self-perceived quality of life often diminishes in multimorbidity. A total of 74 studies representing 2 500 772 study participants who resided in the United States of America (USA), the United Kingdom (UK), and Spain revealed that as multimorbidity increased, quality of life decreased. Ørtenblad et al. (2018) considered quality of life in the context of everyday life and found in addition to the burden of illness, quality of life for people with multimorbidity was significantly strained with the burden of treatment. Factors within this dimension included navigation of day-to-day dilemmas and logistical challenges associated with scheduling and

transportation to medical appointments, coordination of care, fragmented care, and issues of disparities between healthcare provider goals and those of participants. It was identified that everyday life and navigation of the healthcare system must focus on a *patient-centered* approach to mitigate the increasing burden of treatment. Seeking to learn about the experiences of older adults with multimorbidity through a qualitative lens, Ploeg et al. (2017) learned that reduced quality of life in multimorbidity was predominantly experienced as: a) overwhelming, draining and complicated; (b) organizing pills and appointments; (c) being split into pieces; (d) doing what the doctor says; (e) relying on family and friends; and (f) having difficulty getting outside help (p. 1). The literature suggests that engagement and connection with people is important in the context of CCD. Having supportive connections with others is one way to improve a person's sense of quality of life (Sinclair et al., 2016; Wu et al., 2017). Developing supportive connections with others can also help meet some of the needs expressed in the literature and by participants in this study.

Given that existing literature is suggestive of reduced quality of life in internal medicine patients (Mondor et al., 2016; Ploeg et al., 2017) it seems almost paradoxical that participants in this study would be so self-determined, motivated, and engaged in their care. Another way to think about these characteristics is as components of resilience, which may help to explain how participants have remained self-determined, motivated, and engaged.

Resilience is a concept that has gained increasing attention in health and social care. There are competing definitions of resilience depending on context and population, however, the term relates to the ability of a person, people, or system to adapt to disturbances to functioning, well-being, and growth (Masten, 2015). Along these lines, Sturmberg (2018) argued resilience is a property of all complex adaptive systems, ranging from eco-cellular to physiological and

individual coping. He proposed that the principles of positively adapting to perturbations in complex adaptive systems can be applied to complex systems such as healthcare. Resilience, then, can be a means through which positive adaptation and advancement is achieved in the lives of patients facing adversity and in the capacity of those services to respond to patients' needs. This is important, because unless healthcare practitioners within these systems can act to assist resilience building and evaluate their interventions, resilience risks being taken up as a buzzword and the opportunity for helpful practice may be lost.

Thinking about resilience as adjustment and adaptation using a combination of internal and external resources resonates with the data in this study. Most participants described experiences in which they had to adjust and adapt. Participants drew upon their ability to problem solve and negotiate health challenges as autonomous but engaged and self-determined partners with the interdisciplinary team. Along with this, most participants in this study offered descriptions of times when they recognized their health deteriorations were beyond their capacity to manage and they sought assistance from healthcare providers.

The findings of this current study illustrate how resilience is not a fixed state. Like multimorbidity, resilience is vulnerable to fluctuations (Martin, 2018). Resilience requires internal and external resources, which may be more or less accessible depending on a person's circumstances. Despite fluctuations, resilience can be maintained for extended periods of time (Martin, 2018). Recognizing resilience as a relevant concept and site for intervention can shape the way registered nurses practice with and plan care for internal medicine patients. It is possible that nurses could take a more active position in assessing and intervening to help patients build resilience amid ongoing experiences of complexity.

The literature affirms the position that relationships matter for resilience building. Sturmberg (2018) recommends deep conversations that explore what matters most to patients are needed to do resilience-building work. In the absence of being able to arrest physical deteriorations and readmissions, helping patients to build resilience may positively influence perceptions of quality of life and quality of care. This work might also help patients optimize use of internal and external resources for coping and well-being. Cumulatively, this might represent a "win-win outcome for patients and health system sustainability" (Sturmberg, 2018, p. 1328).

From the perspective of registered nursing practice, supporting resilience requires knowing patients in ways that extend beyond disease and being able to act upon that knowledge. Registered nurses are familiar with various frameworks to understand patients' experiences and to respond to patients' needs. In this current study, patients' experiences of complexity, relationships, and care involved the extent to which they were able to make sense of (understand), do what was needed, and make meaning (explain and integrate their experience) about what was happening. These findings align with the theory of salutogenesis (Antonovsky, 1996).

The theory of salutogenesis is predicated on the idea that when an individual can *comprehend, manage, and find meaning* in their circumstances, they possess what Antonovsky (1979) referred to as a sense of coherence. Sense of coherence (SOC) is a cognitive (comprehending), behavioural (managing), and motivational (meaning) construct that has practical application in helping people managing health-related complexities (Antonovsky, 1996; Eriksson & Mittelmark, 2016). When confronted with challenges, Antonovsky (1996) proposed that an individual with SOC will have a higher capacity for resilience because of their capacity to

comprehend their situation, manage using internal and external resources, and find meaning in their circumstances.

In practical terms, nursing practice informed by salutogenesis might involve exploring patients' experiences of their illness and translate what is learned into knowledge, behavioural, and material resources that support patients at various stages of their illness trajectory.

Antonovsky (1979; 1987) suggested that generalized resistance resources (GRR) were the characteristics of coping and how sense of coherence is developed (Appendix F). Antonovsky described how people experience these resources on a continuum between GRR and resistance deficit. Understanding a person's position on this continuum—across the different GRRs—can help professionals to target where intervention may be required.

Working with a patient to develop capacity for resilience may be a valuable contribution for registered nurses to make towards addressing patients' medical complexity. Although illness may not be able to be cured or arrested, patients can still cultivate knowledge, self-determination, and a sense of autonomy and meaning in experience as they engage with health providers and the health system more generally. Data in this study suggest that patients who understand, manage, and make meaning of experience have opportunities to co-navigate their medical complexities as part of the team in ways that might not have been possible without this life skill. In what stands to be a long-term relationship, practice that helps affirm patient as partner seems warranted.

Following a salutogenic model provides some guidance for composing nursing interventions. This is important when it comes to translating a theory into practice. Salutogenesis is not, however, a framework or structure for nursing practice. One framework that might help nurses to imagine and enact salutogenic practice with patients is the Resilience Framework for Nursing and Healthcare (Appendix G; Morse et al., 2021). Morse et al. (2021) argued that

throughout the journey of illness adjustment and recovery, internal compensatory and challenge-related concepts play a vital role in an individual's resilience. Furthermore, the support of external resources, including healthcare providers and loved ones, is essential in cultivating and supporting resilience. Morse and colleagues recognized that enacting practical nursing support for resilience is constrained by a lack of agreed upon definitions and clinical models from which nurses can draw. The Resilience Framework for Nursing and Healthcare is a response to constraints by helping integrate how knowledge and theory around resilience can be applied in practical terms.

Resilience is most often described or discussed as being in relation to something, such as a particular kind of adversity. In the context of health, illness, and nursing practice, Morse et al. (2021) asserted that there are features to adversities experienced by people adjusting to various diseases and illnesses and that these features can inform and shape how resilience can be supported. Morse et al. (2021, p. 6) identified seven index cases in which resilience was significant and adversities were similar: lung transplant, breast cancer, self-awareness of mental health, arthritis, asthma, major trauma, and dependent relationships in persons with Alzheimer's disease. The Resilience Framework for Nursing and Healthcare offers ways nurses can support resilience for patients in an informed and patient-centred way (c.f. Appendix F)<sup>3</sup>. Morse et al. (2021, p. 12) outlined a series of sequential steps to support an individual from a state of *new adversity*, where a stressful event has occurred, towards a state of *recovery/recalibration/readjustment*.

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<sup>3</sup> An example of nursing using the Resilience Framework for Nursing and Healthcare is included in Appendix F.

According to Morse et al. (2021), once a stressful event has occurred, people enter a state of *pre-resilience*, wherein the emotions of processing new adversity are experienced. To support resilience building, a nurse could guide patients through stages of *protecting*, *compensating*, and *challenging*. As a person moves through these coping stages, they reach an enhanced state of resilience, referred to as *outcome equanimity*. Each stage of coping is categorised according to index classes of illness where concepts most applicable to index diseases are identified (Appendix F).

The Resilience Framework for Nursing and Healthcare (Morse et al., 2021) is useful for integrating salutogenesis in practical ways. It provides nurses a framework within which to consider dimensions of salutogenesis and embed them. While the measure of change that we make in each circumstance is never fully known, the framework provides a practical application tool for nurses to enhance the quality of their care and enrich the experience of patients encountering adversity.

### **Specialized Care is Needed**

Despite well-coordinated and well-informed discharges, it was the perspective of most participants in this study that readmission back to the internal medicine setting within 30 days of discharge was unavoidable. Readmission was not experienced on account of unsuccessful discharges, but rather because of medical complexity. Despite close monitoring, medical deteriorations reached a supervised tipping point, where specialized care became unavoidable.

While the need for readmission might be perceived as a failure of care, most participants' readmissions occurred alongside ongoing medical surveillance from GPs and other members of the outpatient interdisciplinary team. This suggests what was happening to participants was beyond the influence of the various resources of participants and their outpatient teams.

Given the prevalence of multimorbidity and its associated complexities, the question of whether internal medicine readmissions can be realistically reduced needs to be re-examined. With an increasing prevalence of multimorbidity in the context of an ageing population, good care accounts for medical complexity. That is to say, when good care happens, nurses and other healthcare professionals recognize and respond to complexity. Of the 17 study participants of this study, four had a history of organ transplant as part of their multimorbidity. Given the burden of treatment and illness is increasing along with multimorbidity, readmission for internal medicine patients may become more of a regular occurrence for a portion of the internal medicine population. While the healthcare team prepares patients to be as successful and resourceful as they can on their discharge home, unforeseen changes in medical complexity cannot always be predicted, necessitating specialized care.

Participants in this study considered readmission to be unavoidable, rather than as a failure on their part or the part of the healthcare system. Participants' experiences show how readmission occurs within a complex, inter-related, interactive context containing complex health and social issues. Amid the complexities associated with illness and readmission, registered nurses need to implement responsive and effective care. The findings of this study show how participants experience healthcare systems as complex, yet they value the relationships they have with providers. Effective and responsive care that addresses and helps patients navigate complexity is required, particularly when readmission may be unavoidable.

## **Chapter Summary**

In this chapter, I have explored how participants of this study experienced readmission back to the internal medicine acute care setting within 30 days of discharge home. The data point to experiences that can be understood through three overarching themes; that *Life with Medical*



*Complexity is Complicated, Relationships Matter, and Specialized Care is Needed.* The findings of this study add to and shape existing literature. In this chapter, I have offered insights drawn from the thematic analysis in this study and from the existing literature to explore possibilities for nursing care in the context of readmission of patients with CCD to internal medicine. In Chapter Six, I discuss nursing implications, recommendations, and limitations of this study.

## **Chapter 6: Conclusion**

This was a study of the experiences of readmission from the perspective of internal medicine patients. Analysis of data revealed three themes that describe patients' experiences. Participants experienced that *life with medical complexity is complicated, relationships matter*, and that *specialized care is needed*. In this Chapter, I conclude the thesis with a summary discussion of the findings and implications of this study. I also make recommendations that arise from the findings and state the methodological and fieldwork limitations of the study.

The findings of this thematic analysis extend the existing literature. The participant data in this study evoke a population with both a heavy burden of illness and a heavy burden of treatment. Patients within the internal medicine population are experiencing complexity of illness and are being treated in complex ways in a complex healthcare system. Given the complexities of vulnerability that can develop within the internal medicine population, internal medicine nurses may be able to practice more effectively if they strengthen relationships with patients. The nurse-patient relationship is central to nursing practice and matters to patients. Within a patient-centered practice, nurses can work effectively with patients to build resilience and adaptation, both for individual patients and, over time, for the systems in which internal medicine care is provided. The findings of this study point towards helpful practice with internal medicine patients. To meet the healthcare needs of this population, internal medicine nurses' knowledge and practice could partially refocus toward a patient-centered, salutogenic approach, rather than emphasizing pathogenic, disease-process-oriented care.

### **Outcomes and Knowledge Translation**

The findings of this study illuminate important aspects of patients' experiences, which have implications for patient care and healthcare delivery. The findings of this research can be

used to inform and educate members of multidisciplinary teams about the readmission experiences of internal medicine patients and ways to respond to their needs. The findings may also be useful for other managerial and administrative stakeholders whose work can benefit from insight into the issue of readmission in the internal medicine context.

Key Stakeholders for this study include all frontline professionals within the multidisciplinary team including staff nurses, physicians, section chief, and unit management. Other stakeholders include AHS administration. Knowledge from this study can inform ongoing efforts by stakeholders to develop upstream, proactive, pre-emptive measures to address patient and health system needs. The results may help inform future planning of how discharge processes are conducted within the acute care setting and follow up with in the community.

### ***Nursing Implications***

The experiences of study participants provide insight into the challenges and complexities alongside which healthcare is provided. Current nursing practice, including advanced practice nursing is sensitized to a highly pathogenic environment. Salutogenesis is a more solution-focused way of practising, which is a different orientation to care; it has implications for how nurses think about and assess patients as well as the ways they plan, determine outcomes, and evaluate care. Within a system of complexity, there exist constraints but also possibilities for doing things differently. The practice of registered nurses can support and extend the ever-evolving healthcare system by developing capacity and supporting resilience among patients. In this thesis, I have argued that nurses may fulfil this goal by integrating salutogenic practices within the Resilience Framework for Nursing and Healthcare (Morse et al., 2021).

## ***Recommendations***

Based upon the research and arguments in this thesis, I offer the following recommendations for practice, education, and research. Practicing nurses might benefit from education that promotes salutogenic (in addition to pathogenic) approaches to patient care. This education needs to attend to practical application. As medical complexity and CCD increase, internal medicine nurses will need skills to assess and respond to patients' resiliency needs with similar attention and urgency to other deteriorating comorbidities or physical deconditioning.

This study was undertaken with a limited sample of participants. Future research into experiences of internal medicine patients with CCD needs to account for population diversity. The participants of this study were all white and spoke fluent English. Research that captures the experiences of vulnerable populations, for whom healthcare is not always experienced as supportive, could inform understanding of readmissions in cultures who are underrepresented in the current literature.

This study has offered some insights into experiences of supportive, yet fragmented care. APNs with clinical expertise in internal medicine have a comprehensive understanding of patient complexity and in-depth knowledge of multidisciplinary team function. They are in an excellent position to comprehensively monitor internal medicine patients while liaising among all interdisciplinary team members offering proactive rather than reactive healthcare interventions and surveillance of internal medicine patients across inpatient and outpatient settings. A helpful future study might explore a role for inpatient and outpatient internal medicine nurse case managers to support fragmented care.

## Limitations

The current study represented the experiences of 17 study participants, which provide a lens into their perspectives. The findings of this study should be interpreted in the context of the sample size and its limitations as well as the scope of the study.

Participants in this study were overwhelmingly positive about their care. Perhaps participants were less likely to be critical *because* of the value they placed on their relationships. Although participants were reminded their care would not be negatively affected by their comments in interviews, the vulnerability conferred by their CCD may have meant they did not disclose further relational complexities. Further research would benefit from accounting for this limitation.

Another limitation of this study is one of reflexivity. Given my experience as an internal medicine nurse, it was not possible for me to separate myself from my perspectives and the experiences that shaped these perspectives in my nursing practice. My biases, as described in Chapter 3, were something that I reflected on so that my preconceptions were not a part of my interview questions and communications with study participants.

## Final Thoughts

The purpose of this study was to learn from patients their perspectives of readmission to the hospital within the internal medicine patient population. Participants of this study experienced that *Life with Medical Complexity is Complicated, Relationships Matter*, and that *Specialized Care is Needed*. The thematic analysis revealed a rich yet complex picture of life with CCD and participants' experiences of readmission. If, as participants suggested, readmission is unavoidable, then nurses need to adapt care in ways that can meet patients' needs and promote capacity, resilience, and well-being.

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## Appendix A

### Permission to Conduct Research at [REDACTED]

This message and any attached documents are only for the use of the intended recipient(s), are confidential and may contain privileged information. Any unauthorized review, use, retransmission, or other disclosure is strictly prohibited. If you have received this message in error, please notify the sender immediately, and then delete the original message. Thank you.



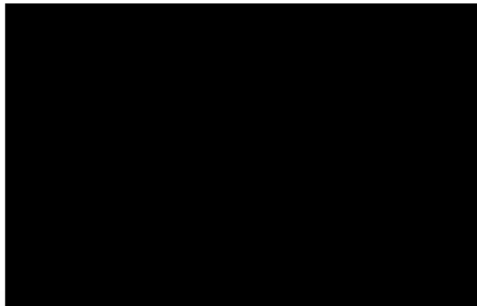
May 17, 2019

To Whom It May Concern,

I give permission, on behalf of [REDACTED] for Shelley deBoer to conduct a qualitative research study regarding patient readmission on the unit.

If you need any further information please contact me as below.

Thank you.



## Appendix B

### Letter to Nurses on Unit ■ Requested Script for Potential Research Candidates



Dear nurses on Unit ■

My name is Shelley de Boer. As you may be aware, I am a registered nurse conducting a research study on Unit ■. As a nurse, I respect patient preferences and would never want to pressure or influence patients into participating in my study. In keeping with AHS policy standards, I ask your assistance in recruiting potential research participants with the following explanation:

Within the internal medicine patient population, a significant number of those discharged from the hospital require readmission within 30 days. Shelley de Boer is a registered nurse who has worked in internal medicine. She is conducting a research study that seeks to gain understanding about why internal medicine patients are readmitted within 30 days of discharge home. The goal of our study is to explore patients' perspectives about this important issue.

Please know that participation in this study is entirely voluntary. Please feel free to decline if you do not wish to participate. The healthcare you receive while staying on Unit ■ is in no way affected by whether you choose to participate and is entirely separate from your care providers and the healthcare you receive while here.

Would you be interested in learning more from Shelley? She will explain all the details and then you can decide if you would like to participate. In the meantime, please accept this recruitment letter for your reference.

Thank you for your time.

## Appendix C

### Recruitment Letter



Dear Sir/Madam,

You are invited to participate in a study that is currently in progress on your unit entitled, *Examining Causes for Readmission in the Internal Medicine Patient Population*

Within the internal medicine patient population, a significant number of those discharged from acute care require readmission within 30 days. Identifying causes of readmission from the perspective of patients will inform health care practice thereby mitigating the factors associated with readmission and ultimately improve the care and outcomes for patients in our care.

The research study is being conducted at [REDACTED] You are being invited because according to our records, you have been readmitted back to the acute care setting within 30 days of your previous discharge from our unit.

To participate, you will be asked to critically consider your perception of the reason(s) behind why you have required readmission. This interview will be 30-60 minutes and will be held at [REDACTED]

There are no known risks associated with participating in this study. Participation is completely voluntary. Your responses to the surveys will remain confidential. If you begin to feel fatigued or wish to stop the interview at any point, please feel free to indicate this to your interviewer.

This study has received ethical approval from the Conjoint Health Research Ethics Board (REB19-0298).

Thank you in advance for your time and participation in this valuable research towards improving resources and supports for nurse educators.

Sincerely,

Dr. Andrew Estefan  
Dr. Cydnee Seneviratne  
Dr. Ruth Swart  
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## Appendix D

### Semi-Structured Interview Questions



Dear Sir/Madam,

Within the internal medicine patient population, a significant number of those discharged from the hospital require readmission within 30 days. As researchers, we would like to understand more about why this is. The goal of our study is to explore patients' perspectives about causes for readmission to internal medicine. Information you provide can contribute to improving the quality of patient care and improving our healthcare system so that it is more effective in the future.

With this in mind, I would like to learn from your perspective:

1. As you reflect to the time just prior to your previous discharge, who was involved in your care/plan for care? What was the experience of working with all of the team players like for you? For example, what were your conversations and interactions like with your healthcare team members? What is your impression of how your care providers understood you? What do you think your care providers understood or failed to understand about you/your healthcare needs?
2. Do you feel like your care providers worked well as a team? What are your overall perceptions of the preparation for your discharge during the time prior to your discharge? Did you have a sense that you understood the goals/objectives of your care providers? What were your conversations and interactions like with the healthcare team? (physician's nurses, pharmacists, social work, physiotherapy, occupational therapy, dietician, anticoagulation clinical, homecare, addictions services, etc.)
3. As you reflect back to your discharge from [REDACTED], how did you anticipate the transition would be for you? What led you to feel this way? Reflecting back, how closely aligned did you feel you and your healthcare team understood the goals for your optimal health/rehab? Where were there similarities/agreement, and where were the misunderstandings/assumptions/breakdown in communication?
4. Is there anything you have come to know/understand from your experience of being discharged and returning to the hospital that you wish you would have known? If so, what are these things?
5. From your perspective, could this current readmission have been avoided? If so, tell me about that.



6. In hindsight, as you reflect on your previous hospitalization experience and the plan for discharge and discharge process, what do we as researchers/healthcare providers need to understand about your experience?
7. Tell me about the first 24 of being home from the hospital. What was that like for you and your loved ones? Tell me about the challenges.
8. How did the first week after being discharged? How did you feel? Did you feel you're your health was improving, staying the same, or declining? What made you feel this way?
9. Looking back, when did it become apparent to you that your health and experience of living day to day was not where it should be? What made you feel that way?
10. As you reflect on the struggles you encountered in the days prior to your readmission, are there any resources, supports, or knowledge that would have assisted you and prevented a further decline in your health status? If yes, what? If no, what are your thoughts and perspectives?

## Appendix E

### Iterations of Themes, Sub-Themes, and Codes

Theme	Sub-Theme(s)	Codes
Life with Medical Complexity is Complicated? Challenging? Allusive? Tenuous? Shaky? Stressful	Chronic complex disease is continually changing	Suddenly... Disease is progressive/becomes more complex Multiples
	Negotiating and adapting to changes in social and familial spaces	What are the negotiation and adaptations?
	The healthcare system is complex	Engagement with the system is complex, but system is accessible/responsive
People Matter	Patient as leader/partner	Self-determination/personal responsibility
	Positive/responsive relationships between team and patient facilitate ...[what?]	interaction/ effective interaction with healthcare providers Positive engagement with healthcare providers
Specialized Care is Needed	Responsibilities of Multidisciplinary Team Multidisciplinary team: Follow up in the community (Family MD, Specialists, RN, lab, pharmacist, liver transplant program)	Disease is progressive/becomes more complex Good care accounts for multimorbidity Management of many conditions is technology dependent (IV, DI Investigations)
	Readmission is unavoidable	the sense that people are

Figure A1. July 9, 2021, Thematic Map

Theme	Sub-Theme(s)	Codes
Life with Medical Complexity is Complicated? Challenging? Allusive? Tenuous? Shaky? Stressful	Chronic complex disease is continually changing	Disease is progressive/becomes more complex Suddenly... Multiples...
	Negotiating and adapting to changes in social and familial spaces	Relationships are impacted
	The healthcare system is complex	Engagement with the system is complex, but system is accessible/responsive
People Matter	Patient as leader/partner	Self-determination/personal responsibility
	Responsive relationships between team and patient facilitate ...[what?]	Effective interaction with healthcare providers Positive engagement with healthcare providers
Specialized Care is Needed	Responsibilities of Multidisciplinary Team	A Supervised Tipping Point (formerly Disease is progressive/becomes more complex) Multipronged Approach
	Readmission is unavoidable	People remain in the system

Figure A2. July 12, 2021, Thematic Map

## Appendix F

### Generalized Resistance Resources within the Salutogenic Model

General Resistances Resources
Material Resources (i.e., Money)
Knowledge and intelligence (i.e., Knowing the real world and acquiring skills)
Ego identity (i.e., Integrated but flexible self)
Coping strategies
Social Support
Commitment and Cohesion with One's Cultural Roots
Cultural Stability
Ritualistic Activities
Religion and Philosophy (i.e., Stable Set of Answers to life's perplexities)
Preventative Health Orientation
Genetic and Constitutional GRRS
Individuals' State of Mind

Figure A3. Generalized Resistance Resources developed by Dr. Aaron Antonovsky (as cited in Mittelmark et al., 2016, p. 57)

## **Appendix F**

### **Example Application of Model to Practice**

The Resilience Framework for Nursing and Healthcare (Morse et al., 2021) offers ways nurses can support resilience for patients in an informed and patient-centered way. Drawing on the experiences of participant 6, who struggled with resilience, the model could be used in practical application.

#### **New Adversity**

For participant 6, adjusting to the reality of having to self-manage his CPAP device at home caused him to feel paralyzed with fear in the days after his discharge home. Using the framework, after being faced with the new adversity, that nightly CPAP treatment would be necessary after discharge home, participant 6 would move into a phase of pre-resilience.

#### **Pre-Resilience**

At this stage, participant 6 would begin the process of recognizing how CPAP would shape and alter his life while also recognizing that recovery/recalibration/readjustment were not attainable. He would become aware at this stage that while he may not feel equipped to negotiate CPAP care independently, that CPAP was integral to his survival. Morse et al. (2021) identified at this stage, fostering protective strategies is vital.

#### **Processing Coping Concepts**

##### ***Protective Concepts***

Protective concepts represent internal qualities that an individual can draw upon to “recognize, accept, and cope with their altered condition”. In participant 6’ case these qualities may include attributes of perseverance, intelligence, and resourcefulness.

### ***Compensative Concepts***

During this phase, participant 6's nurse could utilize coping concept strategies. Referring to Morse et al. (2021) classification system, the nurse would refer to a category of illness related to participant 6's condition and note that protective coping concepts common to health challenges with similar features as his point to concepts of hope, knowledge, social support, and spiritual beliefs. Integrating these concepts into therapeutic conversations, Participant 6's nurse could support him in his adversity as he processed and grappled with his emotions.

### ***Challenge Related Concepts***

At this stage, participant 6 would be coming to terms with the knowledge that the set-up and management of his CPAP device would no longer be the role of a care provider to "do for" him after his discharge home. At this stage, participant 6's nurse could assist him in the details of CPAP management. Participant 6's nurse could support his resilience in processing this transition by assisting him to make a list of obtainable therapeutic goals. In the days prior to discharge home, participant 6 could be encouraged to work through his goals until he was able to successfully set up his own CPAP.

The shift in supporting participant 6 to "do for" himself could have helped him work through the steps of setting up his CPAP so that he could move from a state of fear and paralysis towards a state of equanimity.

### ***Outcome Equanimity***

At this stage, participant 6 would have successfully adapted to his circumstances, and been able to negotiate his CPAP with confidence and acceptance. Having faced that CPAP would be part of his life, he would be able to look towards the future knowing he was competent to manage this skillset.

### **Recovery/Recalibration/Readjustment**

At this stage, resilience is restored or achieved, and participant 6 would move continually to successfully cope, or he would undergo a reoccurrence or remission phase until being confronted with another adversity.

Participant 6 serves as an example of a patient who might have been able to manage his transition more successfully from acute care if he had a stronger sense of resilience. The Resilience Framework for Nursing and Healthcare developed by Morse, et al. (2021) is a basis from which nurses can apply concepts of resilience in practical application, tailored to unique features of adversity common to disease clusters. While it requires nurses to have an extensive knowledge about numerous classifications of illness, internal medicine nurses will find much of this theory is already known to them. What the model provides is a way of conceptualizing common psychological responses to adversity and how they can be connected to common protective, compensatory, and challenge concepts to promote and enhance resilience.

## Appendix G

### The Resilience Framework for Nursing and Healthcare

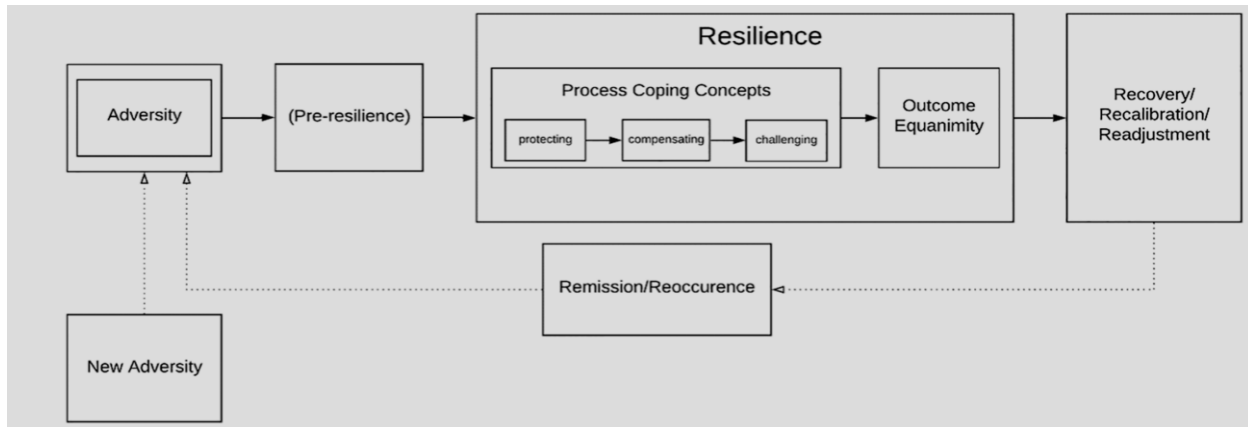


Figure A4. The Resilience Framework for Nursing and Healthcare by Morse (et al., 2021, p. 12)

Classes of Illness® Stages of Coping	Major Solid Organ Transplants	Living with Cancer	Self-Awareness of Mental Illness	Ongoing Chronic Painful Conditions	Episodic Illness	Unexpected or Unanticipated Events	Dyadic Caregiving for the Frail and Ill
Protective Concepts	Baseline Fitness Emotional Health Financial Resources Pessimism/Realism Social Support Spirituality	Acceptance Hope Humor Self-Efficacy Social Support Survival Instinct	Internal Locus Perspective Self-Efficacy Spirituality	Acceptance Autonomy Hope Optimism Patience Perseverance Purpose Social Support	Hope Social Support Spirituality Humor	Acceptance Experience Hope Optimism Social Support Spirituality	Optimism Perspective Resourcefulness Self-Care Social Support Spirituality Well-Being
Compensatory Concepts	Environment Family Support Hopefulness Optimism Spirituality	Adaptation Personal Mastery Optimism	Acceptance Adaptation Hope Humor Mindfulness Social Support Planning Reframing	Patience Purpose Self-Efficacy Self-Growth Well-Being	Empowerment Optimism	Optimism Opportunity Self-Care Social support	Acceptance Communication Knowledge Perspective Self-Care Social Support
Challenge Concepts	Ambition Family Support Mastery Social Support	Balance Communication Determination Endurance Knowledge	Compassion Courage Endurance Knowledge	Autonomy Coping Patience Perseverance Purpose Well-Being	Empowerment Normalization Self-Esteem	Acceptance Adaptation Inspiration Mentor Perseverance Social Support	Knowledge Mastery Meaning-Finding Perspective Self-Efficacy Social Support Spirituality

Figure A5. Concepts Sorted into Classes of Illness by the States of Coping (Morse et al., 2021, p. 11)